

**PROJECT PROTOCOL, Revised 21 February 2014**

**1. Full title of project**

Developing indicators of change in NHS equity performance

**2. Aims and objectives**

*Research question:* Can changes in the socioeconomic patterning of health care utilisation and outcomes provide useful indicators of change in NHS equity performance?

*Core objectives:*

- To develop indicators of time series change in socioeconomic variation in NHS utilisation and outcomes that are potentially sensitive to changes in health care delivery
- To analyse the individual level, area level and organisational level NHS and non-NHS determinants of change in these indicators from 2001/2 to 2014/15
- To pinpoint changes in NHS equity performance in specific geographical regions, specific disease areas, and specific points on the patient pathway
- To develop equity “dashboards” that allow local and national NHS decision makers to pinpoint emerging changes in equity performance and understand how their actions are influencing inequalities

*Supporting objectives:*

- To select general indicators and a small number of disease-specific indicator domains for developing groups of specific indicators looking at multiple stages of the patient pathway
- To assess the technical feasibility of indicator group development in candidate disease-specific indicator domains
- To consult a broad range of NHS stakeholders (including policy makers, managers, clinicians, patient groups and members of the general public) about the selection of general indicators and disease-specific indicator domains

**3. Background**

The Health and Social Care Act 2012 gave NHS decision makers a new duty to have regard to the need to reduce inequalities. This duty applies to both national decision makers such as NHS England and local decisions makers such as Clinical Commissioning Groups. However, although NHS decision makers know that socioeconomic health care inequalities exist, they do not yet have a routine approach to quantifying the influence of the NHS on those inequalities. They cannot routinely pinpoint changes in health care inequalities and do not know what impact their actions are having on such inequalities. Our research will equip policy makers, managers and clinicians with the information they need to pinpoint emerging changes in socioeconomic health care inequalities that may be attributable to changes in NHS delivery, so they can take action to remedy harmful changes and promote beneficial changes. The research will help decision makers to address the questions “where are the inequalities in my community?”; “how can I change the delivery of health care to best address them?”; and “did my actions make a difference?”

Numerous performance indicators based on health care utilisation and outcomes are available to decision makers for routine monitoring of the quality of care received by the “average” individual, such as the Health and Social Care Information Centre Indicators for Quality Improvement, the NHS Atlas of Variation in Health Care, the NHS Outcomes Framework and the Public Health Outcomes Framework (Department of Health 2010, 2012). However, it is more difficult to monitor socioeconomic equity in health care utilisation and outcomes. The Department of Health does plan in due course to disaggregate as many NHS and Public Health Outcomes Framework indicators as possible by area deprivation and other factors, though has acknowledged the difficulty of doing so: “one of the underpinning principles when developing this framework has been the need to promote equality and reduce inequalities in health outcomes...Current data collections are limited in the extent to which this is possible... Over time, we will work to improve data collections so that more indicators

can be disaggregated in this way.” (Department of Health 2010). Furthermore, considerable research effort has already gone into cross sectional measurement of socioeconomic variation in health care utilisation and outcomes at individual and neighbourhood levels, allowing for observable need and risk factors. Researchers have identified social gradients in health care utilisation and outcomes favouring socioeconomically advantaged groups both in the NHS (Dixon et al. 2007) and internationally (O’Donnell et al. 2008). However, the fundamental problem with this kind of analysis is that socioeconomic variation in utilisation and outcomes is partly attributable to factors that are not under the control of NHS decision makers – such as socioeconomic variation in health needs, behaviours and preferences. For example, one of the indicators in the NHS Outcomes Framework is one- and five-year survival following diagnosis from all cancers. But socioeconomic variation in this indicator may partly or wholly reflect socioeconomic variation in cancer stage at presentation and co-morbidity. So simply disaggregating this indicator by area deprivation cannot tell decision makers much about NHS equity performance without further analysis of the NHS determinants of inequality, such as the influence of NHS cancer screening and detection services at earlier stages in the patient pathway.

Our proposed research will address this problem by examining time series change in socioeconomic variation in health care utilisation and outcomes. We have helped to pioneer this approach by looking at change in socioeconomic variation in hospital utilisation from 2001/2 to 2008/9 in a project funded by NIHR SDO Programme (Cookson et al. 2012, 2011a, 2011b). This earlier work examined time series change in small area socioeconomic inequality in NHS hospital utilisation from 2001/2 to 2008/9, focusing on two general indicators (all elective inpatient admissions and all outpatient appointments) and four specific indicators (hip replacement, coronary revascularisation, gastroscopy, senile cataract). It also developed regression-based methods for (i) need standardisation using primary care data on prevalence, (ii) visualising change in gradients in graphical form and (iii) testing for change in gradients over time. Finally, this earlier work also developed difference-in-difference methods for examining the effects of competition on socioeconomic inequality. We found no substantial changes in the socioeconomic patterning of our six indicators of hospital utilisation between 2001/2 to 2008/9, despite substantial changes in average hospital utilisation with different trends for different indicators. We also found that competition had no substantial effect on inequality in overall elective utilisation, but may if anything have slightly reduced inequality. However, we did not examine change in the socioeconomic patterning of health outcomes.

The present proposal develops and extends our earlier work by:

- examining health outcomes as well as health care utilisation
- looking in-depth at groups of indicators in specific disease domains, including patient level as well as small area level indicators
- investigating the NHS determinants of change, by exploiting natural experiments and by comparing patterns of change at different stages in the patient pathway
- extending the original time period (2001/2 to 2008/9) by five years to 2013/14, to cover an important new period of spending slowdown and change in NHS delivery
- performing sub-national as well as national analyses
- developing equity “dashboards” for presenting findings in an accessible and useful form to local and national decision makers

Our time series approach has an important advantage over most other previous research which has focused on cross sectional variation or, less often, change between two end points. Many of the important and unobservable non-NHS determinants of health care variations – such as socioeconomic variations in early life conditions, living and working environments, cultural norms, health expectations, behaviours and preferences – change slowly or have long delayed effects over decades rather than years (Graham 2009). By contrast, changes in NHS delivery can influence health care utilisation and outcomes over the space of a few years.

Doran et al. (2011) provide evidence that pay for performance incentives in the mid 2000s increased the utilisation of incentivised primary care activities compared with non-incentivised activities. Laudicella et al. (2009) provide evidence that GP budget holding reduced deprivation related inequality in utilisation of hospital care in 1992 and 1993, comparing patients in budget holding versus non budget holding practices and allowing for selection effects. Propper et al. (2010) provide evidence that hospital waiting time targets in the 2000s increased utilisation and reduce waiting times for elective hospital care in England, compared with Scotland. Sheldon et al. (2004) provide evidence that time series trends in utilisation of taxanes for cancer and orlistat for obesity both increased significantly following NICE guidance, though there was no clear change in pre-existing trends for other forms of care including hearing aids, hip prostheses, implantable cardioverter defibrillators, laparoscopic hernia repair, and laparoscopic colorectal cancer surgery.

Evidence that NHS delivery can influence outcomes includes the following. Martin et al. (2008) provide evidence that increased health care spending leads to improved mortality outcomes for cancer and circulatory disease, based on a regression analysis of programme budgeting and mortality data on 295 Primary Care Trusts in 2004/5 allowing for observable need and using a two stage least squares instrumental variables approach to identify causal relationships. Cooper et al. (2011) and Gaynor et al. (2011) provide evidence that hospital competition in the English NHS in the 2000s led to improved outcomes, including overall hospital mortality, length of stay, and 30 day mortality following emergency admission for acute myocardial infarction. This evidence has been criticised by Allyson Pollock and colleagues, and the authors respond to these criticisms in Bloom et al. (2011). Finally, Morris et al. (2008), National Audit Office (2008), and Rachet et al. (2009) all provide evidence that changes in the organisation of NHS cancer services from the late 1990s onwards have influenced the quality and outcomes of cancer care.

Quasi-experimental designs make it possible to identify such NHS effects, setting aside the long-run influence of the non-NHS determinants described above. Of course changes in NHS delivery can have no influence on health care utilisation and outcomes, or an influence that is small and cumulative and takes many years to materialise. A key objective of our research will therefore be to select indicators which do have the potential to respond fairly rapidly to changes in NHS delivery – by focusing on particular health outcomes for particular sub-groups of patients with particular conditions – and which therefore can provide useful indicators of change in NHS equity performance.

Our focus will be on socioeconomic inequality, though in due course it will be possible to examine inequalities due to gender, age and ethnicity. However, time series comparisons of age inequality in utilisation and outcomes may be confounded by age cohort effects (Graham 2009) and technology-age interactions (e.g. improved surgical techniques increasing capacity to benefit among older patients from a given type of surgery), and change in ethnic inequality may be confounded by change in coding practices: coding of ethnicity in HES was poor until the late 2000s (Health and Social Care Information Centre 2011).

#### 4. Need

*Health need:* This research will help NHS decision makers more systematically to identify and address problems of unmet need and substandard quality of care in socioeconomically disadvantaged populations, resulting in the prevention of avoidable mortality and morbidity as well as improvements in quality of care and equity of access.

*Expressed need:* According to the Department of Health, “Tackling health inequalities and promoting equality is central if the NHS is to deliver health outcomes that are among the best in the world.” (Department of Health 2010). The Health and Social Care Act 2012 contains a new duty as to reducing inequalities, which applies both nationally and locally:

- “The Secretary of State must have regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service”
- “Each clinical commissioning group must, in the exercise of its functions, have regard to the need to— (a) reduce inequalities between patients with respect to their ability to access health

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services; (b) reduce inequalities between patients with respect to the outcomes achieved for them by the provision of health services.”

*Sustained interest and intent:* Equity was a founding principle of the NHS and remains of central sustained interest to NHS decision makers as documented above. It is even possible that interest may increase over time, in view of the concern expressed by some commentators that socioeconomically disadvantaged NHS patients may be disproportionately affected by the unprecedented financial pressures facing the NHS in the current decade (Whitehead, Hanratty and Popay 2010).

*Capacity to generate new knowledge:* Previous research in this area has been mostly cross sectional, with limited ability to identify causal impacts of NHS decisions on health care inequalities. Our proposed time series research can generate new knowledge about how NHS decisions influence health care inequalities, by using interrupted time series and difference-in-difference research designs and by comparing patterns of time series change within groups of indicators in the same disease domain at different points in the patient pathway.

*Organisational focus consistent with HS&DR mission:* In seeking indicators sensitive to health care our research is consistent with the mission of the HS&DR programme and its primary orientation towards the organisation and delivery of healthcare. We define health care broadly to include preventive health care funded by the NHS via local authorities. So our indicators will be of interest to Public Health England and Health and Wellbeing Boards – in particular, in relation to the “healthcare public health” domain of the Public Health Outcomes Framework aligned with the NHS Outcomes Framework. However, our indicators will not focus on local authority performance in tackling wider determinants of health such as poverty, crime, employment, education and housing, and so will be of more central interest to NHS England and Clinical Commissioning Groups.

*Generalisable findings and prospects for change:* Research in this area will produce findings of value to the NHS management community and relevant organisations will be able to use the findings in their decision making in ways that bring about change and improvement. The focus on producing “equity dashboards” delivers to decision makers and managers an easily accessible tool for direct use rather than relying on them accessing and interpreting a body of research results.

*Building on existing work:* This research builds on previous NIHR funded work by Cookson (e.g. Cookson et al. 2012, 2011a, 2011b) and Raine (e.g. Raine et al. 2010, Scholes et al. 2012).

### 5. Methods

We first describe the consultation methods to be used during the indicator selection phase (months 1-9), before turning to the analytical methods to be used during the indicator piloting phase (months 10-18) and indicator analysis phase (months 19-36).

#### 5.1 Consultation methods for selecting indicator domains

We aim to develop a manageable number of indicators of socioeconomic variation in health care utilisation and outcomes, including both general indicators and groups of specific indicators at multiple points on the patient pathway in particular diseases. Decisions on the selection of both general and disease-specific indicator domains will be made in an iterative consultation process, as described below. More detailed decisions on specific indicators within each domain will then be made and revisited as the data analytical research progresses. The research team will take into account (a) the views of NHS stakeholders obtained through a consultation process described below, (b) the technical feasibility of indicator development in particular domains, and (c) the views of the independent advisory group. Technical feasibility will be established through the research team’s extensive existing knowledge and experience in this area supplemented where necessary through consultation with NHS analysts and additional targeted literature review and dataset investigation in particular disease domains. We will start with the indicators in the NHS Outcomes Framework, and then move on to examine technical feasibility across a broader range of candidate disease-specific domains. The selection of specific individual indicators within each domain is a more technical issue requiring a series of nuanced and iterative scientific value judgements during the indicator development process.

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The advisory group will meet three times: first, to provisionally select the indicator domains, second, to discuss pilot indicator results and agree any revisions to the list of indicator domains, and third, to discuss full indicator results and dashboard presentation style and other matters relating to dissemination. The provisional decision on indicator domains will be subject to further investigation of technical feasibility as the piloting work progresses. If it proves necessary to make substantial modifications in between the first and second meetings, then we will consult the advisory group by email – with follow up 1:1 phone calls and the option of calling a special additional face to face meeting if necessary.

### ***5.1.1 Consultation process***

We aim to consult a diverse range of NHS stakeholders including policy makers, managers, analysts, clinicians, public health specialists, patient groups and members of the general public in order to feed these views into the advisory group to aid their deliberations on indicator selection. Our aim is obtain a range of views from stakeholders with appropriately diverse backgrounds and perspectives, rather than a comprehensive and representative national sample. The aim of consulting NHS experts is to gather information about perceived NHS health inequality impacts and measures in their particular specialist area of NHS expertise. This will help the research team select indicator domains that NHS experts consider to be sensitive to NHS healthcare delivery, and to provide fertile ground for “natural experiment” studies of the health inequality impact of NHS interventions. The aim of consulting members of the public is to gather information about which measurable healthcare inequalities members of the public see as particularly unfair. This will help the research team select indicator domains and types of indicator that are meaningful to members of the public and help them hold NHS decision makers to account.

A more ambitious aim would have been to conduct a ranking exercise, whereby experts and members of the public are asked to rank a pre-specified list of potential indicator domains. A ranking exercise of this kind might be feasible if the list were small enough for us to provide respondents with detailed information about each domain. However, a comprehensive list would be too large for this since it would have to cover the entire span of disease categories and healthcare activities – i.e. potentially containing hundreds of items, depending on the detail of the classification scheme – and a highly selective list would risk unduly restricting the scope of the consultation. Furthermore, asking people to rank disease areas would likely lead to discussions about which disease issues are more important in general, rather than the more relevant issue of socioeconomic inequality and fairness in healthcare between rich and poor within each disease area.

We will consult NHS experts from diverse NHS organisations through an on-line questionnaire survey. The questionnaire will ask respondents to describe national or local NHS interventions in the past decade or so that they think had a measurable impact on socioeconomic inequalities in health care access or outcomes in England. It will also ask respondents to describe the primary outcomes they would use to measure impact on socioeconomic health inequality. This will furnish the research team with a range of potential NHS interventions in different clinical areas that may impact on health inequality, along with appropriate outcome measures. At a later stage, once we have selected our indicator domains, we will conduct more in-depth discussions with selected clinical experts within those domains and Directors of Public Health to identify suitable natural experiments and to refine our initial list of specific indicators.

We will consult about 30 members of the general public using a one-day “citizen’s panel” meeting in the City of York, as described below in the PPI section. We also aim to obtain approximately 100 responses to our questionnaire from individuals based in a diverse NHS stakeholder organisation. We will not seek an “official” response from the organisation, but rather a personal view from a person with experience relevant to the objectives of this project. If there is no response from a particular individual, we will seek a response from an alternative individual within that organisation through appropriate email and telephone contact, or seek a response from a similar organisation.

We will seek responses from the following kinds of individuals in the following kinds of organisation:

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- National decision makers and analysts in the Department of Health (e.g. NHS England, Public Health England including health improvement and protection specialists)
- National decision makers and analysts in Arms Length Public Bodies (e.g. Care Quality Commission, Monitor, NICE, Health and Social Care Information Centre)
- Local decision makers in Clinical Commissioning Groups
- Local decision makers in Health and Wellbeing Boards
- Local decision makers in NHS Hospital Trusts
- Professional associations (e.g. various Royal Colleges, Association of Directors of Public Health, Faculty of Public Health, British Medical Association, British Nursing Association, NHS Confederation)
- Consultancy organisations (e.g. Dr Foster, Right Care)
- Think tanks (e.g. Kings Fund, Nuffield Trust)
- Patient, public and health charity groups (focusing on groups with large general memberships whose staff are free to give a balanced view across a range of different disease domains e.g. Patients Association, Age UK, British Heart Foundation, Macmillan, and others.)

We will administer the survey electronically, identifying email addresses of appropriate individuals through personal project team contacts, web searching and email / phone contact, and then using personal email invitations to complete the survey via the on-line survey tool SmartSurvey.

### 5.1.2 Advisory group composition

The independent advisory group comprises the following members. Cookson and at least three other project team members will join advisory group meetings to present project findings. Meetings will be held in London.

Chair: Brian Ferguson

1. Chris Bentley, Independent Consultant, HINST Associates
2. Sarah Curtis, Professor of Geography, University of Durham
3. Tim Doran, Professor of Health Policy, University of York
4. Brian Ferguson, Deputy Director (Northern & Yorkshire), Public Health England
5. Steve Field, Deputy National Medical Director, NHS England
6. Donald Franklin, Senior Economist, Department of Health
7. Peter Goldblatt, Deputy Director, UCL Institute for Health Equity
8. Anne Griffin, Health Inequalities Team Leader, Department of Health
9. Iona Heath, Past President, Royal College of General Practitioners
10. Ian Holmes, Head of System Alignment, NHS England
11. Azim Lakhani, Head of Clinical Analysis, Information Centre for Research and Development Health and Social Care
12. Nicholas Mays, Professor of Health Policy, LSHTM
13. Alan Maynard, Chair, York CCG, and Professor, University of York
14. Lara McClure, Lay Member
15. Mark Petticrew, Professor of Public Health Evaluation, LSHTM
16. Carol Propper, Chair in Economics, Imperial College London
17. Wim Troch, Lay Member

### 5.1.3 Criteria for indicator selection

#### Criteria for selection of indicator domains

1. **Burden of disease.** We need to select conditions that NHS decision makers and the general public consider important. We also need to select conditions with a sufficiently large patient population to construct statistically stable indicators. Burden of disease is a measurable though imperfect proxy for both of these desiderata.
2. **Availability of indicators in QOF, HES and ONS mortality data.** We need to construct statistically stable indicators at national and sub-national level, for multiple stages of the patient

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pathway, from comprehensive patient level and small area level data on the entire English population, with a comparable time series going back to at least the mid 2000s. In the first instance this restricts us to common conditions for which indicators are available in QOF, HES and ONS mortality data. We will later explore ways of expanding our indicator sets using other data sources.

3. **Availability of quasi experiments.** We need to conduct retrospective “quasi experiments” that provide useful evidence about the effects of past NHS interventions on health inequality. This requires the existence of relevant NHS interventions in the 2000s which (a) were likely to influence socioeconomic health inequality, (b) allow the construction of a suitable control group due to geographical variation in delivery such as differential timing of intervention roll out in different geographical areas, and (c) are relevant to the design and implementation of potential future NHS interventions.
4. **Synergy between the domains.** We only have research capacity to examine 2 or 3 condition specific domains in addition to the general domain. So we need to select a coherent set of domains that differ in important clinical respects and add value in allowing us to draw diverse methodological lessons. Once the methods are developed, NHS analysts can then produce methodologically similar indicators for a wider range of domains.

### Criteria for selection of specific indicators within each domain

1. **Face validity to NHS stakeholders.** We need to select indicators that NHS decision makers, clinicians, patients and the general public consider credible, meaningful and useful.
2. **Sensitivity to NHS intervention.** We need to select indicators that potentially respond to NHS interventions, and are not largely beyond the control of the NHS.
3. **Impact on health inequality.** We need to select indicators that potentially impact on broader inequalities in health.
4. **Availability in QOF, HES and ONS mortality data.** We are initially restricted to indicators of this kind, as explained in the domain selection criteria.
5. **Statistical stability at national and sub-national levels.** We need sufficiently large event counts in each deprivation quintile group to detect time series change in inequality at national level (pop ~53m). For the sub-set of indicators included in “local” equity dashboards we also need statistical stability at sub-national NHS levels. Ideally, it is also useful if indicator population denominators can be split by subgroup e.g. by age group and gender.
6. **Coverage of inequality in both access and outcome**
7. **Coverage of inequality at multiple stages of the patient pathway**
8. **Coverage of inequality in multiple domains of the NHS Outcomes Framework.** The NHS Outcomes Framework has five domains: 1. preventing people from dying prematurely, 2. enhancing quality of life for people with long term conditions, 3. helping people to recover from episodes of ill health or following injury, 4. ensuring that people have a positive experience of care, and 5. treating and caring for people in a safe environment and protecting them from harm.
9. **Synergy between indicators.** We need to select a coherent basket of indicators that complement one another and provide as much useful information as possible. The value of the whole basket of indicators should be more than the sum of its parts.
10. **Relevance to quasi experiments.** Other things equal, we prefer to focus on indicators that can be used to evaluate suitable “quasi experiments” in this domain.

In line with criterion (1), we have decided to include indicators of inequality in GP supply and hospital waiting time in our equity indicator sets, as well as indicators of healthcare utilisation and outcomes. This decision was taken following our first advisory group meeting in November 2013, in response to views expressed by members of the public during our public consultation.

We will also consider adding a “control group” of indicators for which one would not expect socioeconomic variation to be sensitive to change in NHS delivery, such as mortality from causes considered not amenable to health care.

### ***5.1.4 Indicator domains selected following the first advisory group meeting***

After our first advisory group meeting in November 2013, the following indicator domains were selected:

1. General
2. Coronary heart disease
3. Diabetes

A number of potential “quasi experiments” were discussed, with promising candidates including (1) the Health Inequalities National Support Team (HINST) programme of support to Spearhead areas from 2007-9, and (2) changes to incentives within the Quality and Outcomes Framework; both of which could use the coronary heart disease and diabetes indicator domains as a data platform.

The advisory group also suggested that at a later stage we consider incorporating a mental health dimension within some of these indicator domains, for example by comparing physical health outcomes for patients with and without severe mental illness.

### **5.2 Analytical methods for developing the performance indicators**

Since we have not yet selected the indicators, it is not possible to give highly specific details of our methods – for instance, specific study designs, sample sizes, outcome measures, covariates and so on. Instead, however, we describe the general methods to be used, irrespective of the indicators selected, with illustrative examples relating to two possible disease-specific indicator domains involving social gradients that may be sensitive to change in health care delivery: colorectal cancer and coronary heart disease. We could have used examples from a range of other disease domains, and use of these examples does not necessarily imply that either will be among the indicator domains ultimately chosen by our advisory group.

*Design and conceptual framework:* For each indicator, the basic approach will be to estimate cross sectional association between socioeconomic characteristics and an indicator of utilisation or outcome – a “social gradient”, for short – using a patient level or small area level regression model, and then to track time series change in this gradient. The regression model will include covariates to adjust for individual or small area level risk factors such as age, sex and morbidity, and for clustering within organisations or geographical areas. The estimated model can then be used to set confidence intervals around the gradient and to test whether any observed change over time is statistically significant. Different model specifications can be used to examine an appropriate range of inequality measures reflecting different inequality concepts, including gaps and absolute indices as well as ratios and relative indices. Once this basic indicator measurement work has been done, one can then proceed to analyse NHS determinants of change. There are two main ways of doing this. First, using quasi-experimental designs such as interrupted time series and difference-in-difference studies. Second, by comparing patterns of time series change within the same disease domain between specific indicators at different stages of the patient pathway. For instance, if we observe a relative improvement in the quality of primary care in deprived areas (e.g. through increased case finding and improved control of blood pressure and cholesterol in patients with cardiovascular disease) we can check whether this is followed by a relative reduction in emergency AMI admissions and cardiac mortality rates.

The appropriate quasi-experimental analyses to perform will depend on prior investigation of plausible NHS determinants, which will require literature review and consultation with specialists in the disease domain under consideration. However, just as an example, we could examine whether the introduction of the NHS National Service Framework for Coronary Heart Disease (NSF CHD) from 2000 led to reductions in social gradients in mortality from CHD and in utilisation and outcomes of CABG and PCI revascularisation procedures, allowing for change in population risk factors. One element of the NSF CHD was the establishment of minimum surgery volumes. This may have reduced the gradient in outcomes, if disadvantaged patients were in the past more likely to attend poorly performing local hospitals rather than large specialist centres with good outcomes. One could use an interrupted time series design or, more ambitiously, a difference-in-difference design based on comparing a “control group” of areas served by hospitals with historically high volumes against a



“treatment group” of areas served by lower volume hospitals. As another example, we could use quasi-experimental designs to examine the influence of the English bowel cancer screening programme on the social gradient in 28-day mortality following colorectal surgery and one year survival following diagnosis. One possible cause of these gradients may be relatively late detection of cancer among disadvantaged groups. This may result in disadvantaged patients having relatively advanced forms of bowel cancer before they come to the attention of the NHS. If so, the English bowel cancer screening programme, which was piloted in 2003-5 and rolled out nationally from 2006, might be expected to reduce the social gradient in outcomes through earlier detection of cancer in disadvantaged patients. On the other hand, since uptake is higher among more advantaged patient groups, the programme may conceivably have increased the social gradient in outcomes.

*Sampling:* Statistical power to detect meaningful changes in social gradients at national level will be an important criterion for selecting indicator domains and indicators. As Martin Bland has written, the key issue is not so much about significance levels as how well we can estimate differences (Bland 2009). However, the confidence intervals around our estimates will depend on nuanced technical choices about indicator definition and construction, which cannot be fully specified in advance of indicator piloting. So assessment of statistical power will have to be an iterative process. Our approach will be to collect comprehensive national data on the entire relevant population of English NHS patients – typically hundreds of thousands and often millions of patients for the common disease domains we are likely to study. However, these large population sizes will not always yield adequate power to detect meaningful changes in social gradients – say a 5 to 10 percentage point change in a rate ratio or slope index of inequality – when it comes to less common outcomes such as mortality and re-admission. Furthermore, many disease specific indicators will have adequate statistical power to detect significant time series change in social gradients at national but not local level. These considerations will guide our selection and we will only work with sample sizes where we can be assured that findings will be robust. The process of ensuring we have enough power to detect meaningful changes in the social gradient is iterative, and cannot be fully resolved in advance of the indicator piloting stage. In our previous work on utilisation we had very large sample sizes of hundreds of thousands of hospital admissions per year, which were more than adequate to estimate meaningful changes in social gradients. In our proposed work, however, we will sometimes be working with smaller samples of only thousands of negative health outcomes (e.g. deaths, re-admissions) per year. For example, Burns et al. (2011) report a total of 9,819 reoperations (6.2%) out of a total of 158,847 elective colorectal surgery operations over a 8 year period from 2000/1 to 2007/8, which works out at just over 1,200 reoperations per year out of a total of about 20,000 operations a year. (Plus another 750 or so a year if we include emergency surgery - there were 6,156 reoperations following emergency surgery, a rate of 7%). However, we will always be able to increase our power to detect meaningful change by pooling data over 2 or 3 years, by refining the indicator definition, by focusing on specific patient sub-groups at higher risk of negative health event, or by using different model specifications (for example, by splitting area deprivation score into larger sub-groups). We may also explore combining multiple indicators in the same analysis, for example using latent class analysis whereby one models the residuals or “latent components” as a function of deprivation and time, after controlling for covariates. By pooling data from multiple different indicators, this kind of analysis will of course substantially increase our power to detect meaningful overall effects.

For example, imagine we want to examine change between 2001/2 and 2010/11 in the patient level association between area deprivation and reoperation following colorectal surgery, adjusting for age, sex and co-morbidity. We can do a power calculation to estimate the approximate standard error if we know the sample size, event rate, and the specification of the social gradient. For example, imagine we use logistic regression to compute adjusted reoperation rate ratios between the most and least deprived quintile group, and then test for change over time. Adjusted odds ratios will be approximately equal to the ratio of the two counts, given that the proportions will be small, the denominators almost identical, and the adjustment will not have a huge effect. The standard error of a Poisson count is the square root of the count, and the standard error of the log count is approximately  $1/\sqrt{\text{count}}$ . The standard error of the log ratio is thus  $\sqrt{1/\text{count}_1 + 1/\text{count}_2}$ . The standard error

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of the log ratio of two such ratios is therefore  $\sqrt{1/\text{count1} + 1/\text{count2} + 1/\text{count3} + 1/\text{count4}}$ . So if we want to compare two ratios of most deprived fifth to least deprived fifth,  $r_1$  and  $r_2$ , where the expected count in the least deprived fifth is  $k$ , the approximate standard error will be  $\sqrt{1/k + 1/kr_1 + 1/k + 1/kr_2} = \sqrt{(2 + 1/r_1 + 1/r_2)/k}$ . So for any  $k$  we can estimate the approximate standard error for  $\log(r_1/r_2)$ . This would enable us to estimate the likely width of the confidence interval; and also to say what  $r_1/r_2$  we could detect with specified power. However, all of these key parameters depend on nuanced methodological choices (about data pooling, indicator definition and model specification) that cannot be finalised in advance of doing the research.

*Setting/context:* In general we will examine utilisation and outcomes for all relevant patients in the English NHS. However the specific medical and organisation settings will of course depend on the indicators chosen.

*Data collection:* We will use three main sources of comprehensive national data:

- Hospital Episode Statistics data on NHS hospital utilisation and outcomes in England, at both patient and small area levels (available annually for our entire study period)
- Quality and Outcomes Framework data on primary care quality, disease prevalence and lifestyle in England, attributed from GP practice to small area level using data on area of residence of practice populations (available annually from the mid 2000s)
- ONS mortality data at small area level (available annually for our entire study period)

To measure socioeconomic characteristics we will use small area level deprivation indices (based on claims data), in particular the IMD income domain but also the skills domain to check how far social patterning differs between education-related and income-related deprivation. To allow for small area population size and age-sex structure we will use ONS mid-year population estimates updated using data from Census 2011 which will be released during the lifetime of the project.

*Data analysis:* We will measure year-by-year change in indices of deprivation-related inequality in health care utilisation and outcomes, using both small area level and patient level indicators. We will control for observable non-NHS determinants of change in small area analyses by modelling change in small area population need (e.g. using ONS data on age, sex and ethnic mix and QOF data on disease prevalence, smoking and obesity) and in patient level analyses by modelling change in patient risk factors (e.g. using HES data on age, sex, ethnicity and diagnoses). We will also perform sub-national analyses to develop equity dashboards for sub-national decision makers such as Clinical Commissioning Groups and Health and Wellbeing Boards. Our focus on comprehensive national data and time-fixed small areas allows us the flexibility to choose the most appropriate time-fixed geographical boundary for the analysis in hand, depending on statistical power and decision maker preferences. We will consult stakeholders to identify plausible NHS determinants of change for particular indicators, and use interrupted time series and difference-in-difference designs to identify causal impacts of those NHS determinants.

### **Contribution to collective research effort and research utilisation**

To facilitate knowledge mobilisation we will develop equity performance “dashboards” that help local and national decision makers to monitor changes in NHS equity performance in particular geographical regions and disease areas at particular points on the patient pathway. By an “equity performance dashboard” we mean a concise way of presenting decision makers with useful information about NHS equity performance in their area of responsibility, in a manner they can quickly digest and act upon – rather like car drivers or airline pilots use their dashboards of information about vehicle performance. One way of doing this is in the form of one or two pages of paper, densely packed with information about different aspects of performance in a standardised format that decision makers can read and understand quickly once they are familiar with the basic format. Dashboards can also be presented via electronic devices such as overhead projectors, laptops, tablets and mobile phones. Information is often presented in multiple small “micro charts” representing different domains of performance, along with suitable warning signs such as an overall

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performance “grade” or a colour coded “traffic light” system. This summary “dashboard” may also be accompanied by a more detailed report, to which decision makers can refer if they want more in-depth information and context about particular indicators. We will iterate our way towards an appropriate dashboard format by trying out various different formats during development and piloting stages, including seeking views on alternative formats from potential end users (i.e. national and local decision makers).

We will select the appropriate geographical level(s) for dashboard development following indicator piloting work. We will initially use a multi-level modeling approach with three nested sub-national geographical levels: (1) CCG, (2) NHS local area team, (3) Clinical Senate Area. We can then take decisions about the appropriate geographical level(s) for constructing local NHS equity dashboards at a later stage, once we have more information about the width of confidence intervals and the stability over time of different indicators at different geographical levels.

In developing these dashboards we will draw on the considerable experience of co-applicants Goddard, Ferguson and Goldblatt in developing performance indicator tools for the NHS, and consult with relevant NHS decision makers. We will in particular draw on the experience of the YHPHO which has produced a series of 'inequalities dashboards' for the region and for individual local authorities (the url to the collection is below):

<http://www.yhpho.org.uk/default.aspx?RID=84683>

These have been extensively piloted and used, e.g. by Yorkshire and Humber SHA Board - ie a mixture of executive and non-executive directors. Feedback suggests that typically people at first find these a little 'busy' with a lot of information, but once they become familiar with them, they find them useful. Dr Foster and other commercial companies also use this format extensively in their work with the NHS, for example, in monitoring acute trust performance where hospitals want to see what is happening on a regular and frequent (usually monthly) basis. We will pilot our dashboards at the second and third meetings of our advisory group, and in small group meetings with analysts and decision makers from (1) NHS England and (2) a Clinical Commissioning Group. We can arrange these meetings through advisory group members and through our contacts with CCGs locally.

The ultimate test of how far our indicators are useful will of course be how far they are actually used in practice after the project finishes, and how effective they are shown to be. However, we will obtain feedback about the potential usefulness of our indicators and dashboards throughout the course of the project so we can fine tune them accordingly – including feedback from the consultation with stakeholders about indicator selection, the piloting of equity dashboards with our advisory board and small groups of local and national decision makers, and the dissemination of diverse project outputs to academic and stakeholder audiences.

### **Plan of investigation and timetable**

A monthly project timetable is shown in the attached flow chart, which has been produced in the form of a Gantt chart giving detailed information about the scheduling of activities.

### **Approval by Ethics Committees**

We obtained University of York Department of Health Sciences Research Governance Committee approval for the consultation process in May 2013. External ethics approval is not required for our questionnaire and citizens' panel process, though research governance approval is required for consulting NHS staff (as opposed to policy makers and non-NHS staff). We will observe CHE data security policy in the use of HES, primary care and mortality data including strict protocols for the use of identifiable patient level data, with which CHE staff are highly experienced. Additional approvals may be required for use of sensitive data later in the project, for example if we want to refine our HES based indicators using data from one of the six national cardiovascular clinical audits managed by NICOR (the National Institute for Cardiovascular Outcomes Research), or if we want to refine our QOF based indicators using data from the CPRD (Clinical Practice Research Datalink).

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Our research team has good links with NICOR through advisory group member, Dr Chris Gale, and with CPRD through advisory group member Professor Tim Doran.

### **Project management**

Cookson will act as project manager. The core project team will meet weekly, and the co-applicants will hold quarterly meetings, rotated between York and London. The advisory board will meet three times, as described above.

### **Public involvement**

We will consult members of the general public by holding a one day citizen's panel meeting with a sample of 30 adult members of the public stratified by age, gender and area deprivation. Their views will form part of the material provided to the advisory group to guide indicator selection. We will administer the same questionnaire used for consulting NHS stakeholders, interspersed with "expert" presentations on the underlying issues and opportunities for group discussion and reflection, eliciting both "initial" and "final" responses from panel members. We will also run an on-line public survey alongside our citizens' panel, with survey recruitment piggybacking on recruitment for the citizens' panel. This allows us to get views from a larger sample of members of the public, though obviously not at the same level of depth as in our citizens' panel discussions. It also means that people won't feel excluded from the consultation if there are no spaces left for them to join our citizens' panel.

The final results, including comments and suggestions for additional domains and key themes from the day's discussion based on notes taken by three members of the research team, will be summarised in a briefing note to the advisory group. We will cover expenses and a one off payment in accordance with INVOLVE "payment for involvement" guidelines. The meeting will be held at the Kings Manor in the City of York, to make attendance as easy as possible for members of the public. During the citizen's panel, we will recruit two lay members for our advisory group, selecting members of the panel who are willing to engage with the experts on our advisory group.

### **Expertise and justification of support required (inc. staff numbers and grades)**

The project is a collaboration between the University of York, University College London, Imperial College London and the University of East Anglia. The multi-disciplinary team includes experts in economics (Cookson, Goddard, Laudicella), epidemiology (Goldblatt), public health (Raine, Ferguson), primary care (Fleetcroft) and primary care data (Dusheiko). Data manipulation and analysis will be conducted at the University of York Centre for Health Economics (CHE).

Dr Cookson is a Reader at the University of York Centre for Health Economics (CHE) who has made innovative methodological contributions to the study of equity in health and health care. He was PI on the recently completed NIHR SDO project 'The effects of choice and market reform on inequalities of access to health care', whose findings received attention in the national media, and is a member of the Marmot Europe Review economics task group and the NHS Outcomes Framework Technical Advisory Group. He will contribute 40% of his time: 15% for project management, 20% for supervising the data analysis, and 5% for meetings with stakeholders and specialist clinicians.

Professor Raine is Professor of Health Care Evaluation, UCL, UCLPartners Programme Director for Population Health, Lead of Health Services Research (HSR) Theme, NIHR UCLH / UCL Comprehensive Biomedical Research Centre, and Fellow of the Faculty of Public Health. She has established an internationally recognised research programme on inequalities in health care and has extensive national and international scientific advisory experience in academic medicine and public health. She will contribute 7.5% of her time to provide epidemiological/ health services input and guidance on indicator selection and interpretation.

Dr Laudicella is a Research Fellow at Imperial College London with substantial expertise in risk adjustment modelling and analysing socio-economic equity in health care. He has specific experience in the data manipulation of Hospital Episode Statistics for the construction of patient level case-mix

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variables and the identification of continuous inpatient spells. He will contribute 10% of his time to help design and supervise specialised aspects of data manipulation and risk adjustment modelling.

Professor Goddard is Professor of Health Economics and Director of CHE. She is a leading expert on health care performance with an interest in health care equity, with extensive experience advising local, national and international organizations including advising the WHO on equity issues. She will contribute 10 days to advise on equity performance indicator design and interpretation and facilitate engagement of NHS policy makers and managers.

Professor Ferguson is Director of the Yorkshire and Humber Public Health Observatory and Co-Director of the Northern & Yorkshire Cancer Registry and Information Service. He will contribute 10 days to advise on equity dashboard development and facilitate engagement of NHS policy makers, managers and public health specialists.

Dr Fleetcroft is a GP and Clinical Lecturer in General Practice at the Norwich Medical School, University of East Anglia, with an interest in the causes of variation in performance in primary care. He has had previous roles as clinical governance lead and GPwSI in clinical education for Great Yarmouth and Waveney PCT. He will contribute 10 days to contribute a GP perspective and facilitate liaison with hospital consultants and clinicians in particular disease areas.

Peter Goldblatt is Honorary Professor of Epidemiology and Public Health and Deputy Director of the Institute for Health Equity at the Department of Epidemiology and Public Health, University College London. He was Chief Medical Statistician at the Office for National Statistics from 1999 to 2008. He will contribute 10 days to contribute a broad health inequality and social determinants of health perspective and to advise on mortality and other data provided by ONS, and on equity dashboard development drawing on his experience with the Marmot indicators.

Dr Dusheiko is a research fellow with over ten years experience analysing primary care data as research fellow at the National Primary Care Research and Development Centre at CHE. He will contribute 10% of his time to provide expertise in primary care data analysis.

We will employ a Research Fellow responsible for data management and manipulation and for the execution of the econometric analyses. The Research Fellow will be based at CHE under the daily supervision of Richard Cookson, and will receive additional supervision from Mauro Laudicella in order to execute the wide-ranging and complex data assembly and modelling tasks required for this project. We will also employ an administrator to help organise the consultation process, including preparing briefing materials, following-up respondents, and preparing results for discussion by the advisory group.

University of York costs:

Unnamed grade 6 researcher 100% FTE to perform data assembly and analysis tasks

Unnamed grade 5 staff 50% FTE for 9 months to perform consultation process tasks

Linda Baille 10 days over 9 months to provide secretarial support for the consultation process

Cookson (40% FTE), Goddard (10 days), Ferguson (10 days), Dusheiko (10% FTE)

Rita Santos (10 days to produce GIS maps of inequality)

Costs for a 1 day citizen's panel meeting

Travel and subsistence costs for annual advisory board meetings, 1:1 meetings with specialist clinicians and analysts, and conference costs for dissemination targeting key academic, policy and practitioner audiences (Society for Social Medicine, European Public Health Association, Health Economists Study Group, International Health Economics Association, HSRN/SDO Annual Conference, NHS Confederation Annual Conference).

Consumable costs for secure data storage fees, database access fees, open access journal article processing fees, book costs and 1 laptop.

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UCL costs:

Rosalind Raine (7.5% FTE throughout the project), Peter Goldblatt (10 days)

Imperial College London costs:

Mauro Laudicella (10% FTE throughout the project) plus travel and 1 UK conference attendance.

University of East Anglia costs

Robert Fleetcroft (10 days advisory input).

### **Planned or active related research grants**

Raine is lead investigator on a number of projects funded by NIHR, Wellcome Trust and L&G examining socioeconomic variation in health care utilisation and outcomes. Goddard is co-applicant on a 5 year Policy Research Programme grant from NIHR on economic aspects of health and social care that uses related datasets and methodological approaches.

### **History of past or existing NIHR programme research**

Cookson held a NIHR SDO grant which was awarded a no-cost extension of 7 months due to delays in accessing data on hospital activity from the independent sector treatment centre programme.

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