## Minimising bias in ethnicity data v0.3

## Version history

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| v0.1 | 17/01/2022 | First protocol draft including the two objectives of the project CCU0037 |
| v0.2 | 15/02/2022 | Draft splitting and creation of the individual protocols: CCU037\_001 and CCU037\_002.  From now on, following versions in this history will belong to CCU037\_001. |
| v0.3 | 23/03/2022 | Protocol draft cleaned |
| v0.3 | 05/10/2022 | Protocol v0.3 upload to ccu037\_01 Box folder |

## Lay summary

Inequality in health has been highlighted by the COVID-19 pandemic, where people from ethnically diverse backgrounds were disproportionately affected. But we know inequity is not limited to the pandemic as it is a long-standing, multi-faceted issue.

An example is technology for predicting a person’s future health risks. This involves routinely collected health information, which is fed into a computer model which in turn produces a health risk score for a patient, and that is used by doctors to decide patient care. If there is bias in the data or bias in the model, the doctor can potentially make wrong decisions and patients can get the wrong care or no care, meaning some groups of patients might inappropriately be prioritised over other for booster vaccines, hospital beds, or life-saving treatments, which in turn can affect patient and public trust, and cost the NHS.

This proposal aims to improve existing technology for predicting personalised future risk of health conditions, particularly those affecting overlooked groups of patients. We aim to do so by a) improving the way recorded ethnicity is used in research, and b) improving the modelling process to build risk prediction models tailored to ethnicity groups and therefore more reliable in practice.

We propose to develop a calculator to predict cardiovascular disease (CVD) in COVID-19 patients as an example to demonstrate our approach, as here ethnic biases are known to exist. As inequity in data and models affects all disease areas, our approach is sustainable and can be applied to other clinical areas in the NHS. The calculator can be used by public to guide lifestyle choices, and by doctors to provide better care.

The publicly available algorithm for improving information on ethnicity can be used by researchers nationwide doing health research involving ethnicity.

This work will be based on anonymised health information that represents almost everyone currently living in England and Wales. By extending to Northern Ireland and Scotland in future, we hope that this work will help to make health equal and fair for everyone in the UK.

## AUTHORS

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## TITLE

Improving methods to minimise bias in ethnicity data for more representative and generalizable models, using CVD in COVID-19 as an example.

## SHORT TITLE

Minimising bias in ethnicity data

## BACKGROUND

The importance of ethnicity in understanding and addressing inequalities in healthcare access, patient experience, and patient outcomes is well-recognised [1-5], but it has been highlighted by the COVID-19 pandemic, where people from ethnically diverse backgrounds were disproportionately affected [6].

Much health research and clinical practice, including predicting risk of developing health conditions, relies on data collected by healthcare professionals in primary (e.g., GP practices) and secondary (e.g., hospitals) care settings. Patient self-reported variables (e.g., smoking, ethnicity) are not always collected, as individuals can decline to share them, and healthcare professionals may not ask for or record them. At least one-third of patients are missing ethnicity records [7]. When recorded, ethnicity is often inaccurately coded [7-9]. Literature focuses on a subset of ethnicity Read codes [10, 11], often collapsed into five to nine categories [4, 12, 13]. This oversimplification, differences in census classifications over time [14], conflicts in individuals’ recorded ethnicity, and speculative recording contribute to inaccuracies.

Many prediction models do not consider ethnicity [15] or estimate/impute missing ethnicity using invalid assumptions. Although ethnicity’s missingness can vary by ethnicity, many well-known clinical risk prediction tools [16-19] assume missingness at random. The result is inaccurate, biased ethnicity estimates. Prediction models are generally not trained, tested, and externally validated on data representative of all ethnic groups [15, 16, 18, 19]. They may not capture differences between minority/ethnic groups in the magnitude of predictor-outcome associations or assess predictor-ethnicity interactions. Consequently, these tools can cause over- or under-estimated outcome risks [20] and thus inequality in healthcare provision:   
if there is bias in the data or bias in the model, the doctor can potentially make wrong decisions and patients can get the wrong care or no care, meaning some groups of patients might inappropriately be prioritised over other for booster vaccines, hospital beds, or life-saving treatments, which in turn can affect patients’ lives and public trust, and cost to the NHS.

All of the >100 published COVID-19 prediction models are at risk of bias and unsuitable for triaging patients in clinical practice [20]. Against the backdrop of health inequalities exposed by the COVID-19 pandemic [21-25], these issues motivate the need to fill gaps in ethnicity data, identify ethnicity-specific predictors, and build accurate clinical risk prediction models that are suitable for minority and ethnic groups.

This proposal will develop an approach for modelling observational data that addresses ethnicity coding and builds representative models suitable for ethnic groups by predicting cardiovascular disease (CVD) in COVID-19 patients as an example to demonstrate our approach, as here ethnic biases are known to exist. As inequity in data and models affects all disease areas, our approach is sustainable and can be applied to other clinical areas in the NHS. The calculator can be used by public to guide lifestyle choices, and by doctors to provide better care.

## RESEARCH QUESTION

To improve the correctness, completeness, and granularity of ethnicity in routinely collected data such that more representative and generalizable models can be developed, using CVD in COVID-19 as an example.

## RESEARCH PLAN

## Objective 1. Implementing a novel approach to improve correctness, completeness, and granularity of ethnicity information using routinely collected data

*Study population*:

All individuals meeting the following inclusion criteria will be recruited:

* Recorded in GDPPR table
* aged ≥18 years
* >1 year of records available

Individuals will be excluded when:

* Not included in GDPPR table
* aged <18 years
* <1 year of data before index date
* Missing sex
* Invalid age (i.e., age > 115 or missing)

*Methods:*

1.1: Improving ethnicity correctness.

Ethnicity records may be inconsistent (i.e. different ethnicity recorded at different GP/hospital visits), or non-specific (e.g. “other”). Using all 290+ medical codes available for ethnicity and adopting advanced curation techniques (e.g. applied in [26]) our proposed algorithm will add more accuracy and granularity so that a patient’s ethnicity data are consistent and granular.

1.2: Improving ethnicity completeness.

Ethnicity records in GDPPR may also be missing. To complete them we will use the ethnicity data recorded in other linked tables across the TRE.

so that ethnicity data are more complete.

1.3: PPI consultation.

Two half-day focus groups with 6-8 PPI representatives from diverse ethnic groups, hosted by the Centre for Ethnic Health Research, will support Objective 1.

## DATA SOURCES

For both Objectives 1 and 2, the same approach will be used:

* NHS Digital (55 million records) will be used for model development (and internal validation)
* SAIL (3.2 million) will be used for external validation.

## REQUESTED DATASETS

### NHS Digital TRE for England

* Primary care data
  + GPES Data for Pandemic Planning and Research (GDPPR)
* Secondary care data:
  + Hospital episode statistics Admitted Patient Care (HES APC)
  + Adult Critical Care
  + Outpatients
  + Accident & Emergency
  + SUS: Secondary Uses Service
  + SUS/Uncurated Low Latency Hospital Data (Admitted Patient Care, Outpatients, Critical Care)
  + Emergency Care Data Set (ECDS)
* Death registers:
  + Office for National Statistics (ONS) death registration records
  + NHSD mortality data review

### Secure Anonymised Information Linkage Databank (SAIL) for Wales

* Primary care data
  + Welsh Longitudinal General Practice (GPCD) - daily COVID codes only.
  + Welsh Longitudinal General Practice (WLGP)
* Secondary care data:
  + Critical Care Dataset (CCDS)
  + Outpatient Dataset for Wales (OPDW)
  + Outpatient Referral Dataset (OPRD)
  + Patient Episode Dataset for Wales (PEDW)
* Death registers:
  + ADDD: Annual District Death Daily (ONS Deaths)
  + ADDE: Annual District Death Extract (ONS Deaths)
  + CDDS: COVID-19 Consolidated Deaths
* ITU:
  + ICCD: ICNARC – Intensive Care National Audit & Research Centre   
     (COVID-19 only admissions)
  + ICNC: ICNARC – Intensive Care National Audit & Research Centre   
     (All admissions)
* Prescribing/ Dispensing
  + Wales Dispensing Dataset (WDDS)
* Others:
  + CENW: Office of National Statistics Census (2011)
  + WDSD: Welsh Demographic Service Dataset
  + WRRS: Welsh Results Reporting Service

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