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**Data Strategy for Health and Social Care consultation**

**Coalition for Racial Equality and Rights**

**August 2022**

(Originally submitted via Citizen Space)

**Understanding the importance and implications of equalities monitoring data for policy making.**

Regarding the understanding of what data exists and where to find it and how to access data, to improve the availability and accessibility of health and social care data, standardised practices for data collection and centralised platforms for data sharing must be better utilised. This must extend beyond the health and social care sector, linking in closely with the work and outcomes of the Equality Data Improvement Project and Equality Evidence Strategy to ensure that equalities data is robust, accessible and highly comparable.

Ideally, this would involve increased engagement with central equalities infrastructure, such as the Equality Evidence Finder and the racial equality evidence base maintained by the Scottish Government’s Race Equality Interim Governance Group’s proposed race equality observatory. Examples for how this may work in practice can be sought from the NHS in England’s recent creation of a Race and Health Observatory and approaches to evidence and data.

Improving the availability and accessibility of these data would allow health and social care providers, service users, and external researchers to better understand structural and systemic issues and inequalities, develop a clearer picture of health and social care pathways to inform decision making, and improve the quality and efficiency of any research linking in with the health and social care sector.

**Regarding the importance and implications of equalities monitoring data for policy making**

As highlighted by the COVID-19 pandemic, a lack of adequate data to monitor the health outcomes of BME groups impacts the ability of health services to provide for minority ethnic needs. Health and social care workers must be made aware of these inequalities and how data scarcity contributes to them through specific training programmes. This must be part of general equalities and anti-racist training but also expanded upon for those specifically working in a data monitoring and analysis capacity within the sector.

Health and social care professionals must learn to treat ethnicity information as an essential piece of data – one of equal importance to age, sex and other primary characteristics.

Civil Servants involved in developing this strategy will no doubt be aware of the concurrent development of an Equality Evidence Strategy to be implemented in 2023, and whilst linking to this is important, this will not negate the need for an ethnicity data focus for the Health and Social Care Data Strategy.

Within CRER’s review of race equality policy since devolution (undertaken on behalf of Scottish Government), we identified that opportunities for change on race equality are routinely missed when developers of strategies expect that a separate, equality-focussed strategy will consider race in their stead and thus fail to make appropriate commitments.

We would urge Scottish Government to ensure that action to improve ethnicity data availability and access is explicitly included in the Health and Social Care Data Strategy. These considerations should be present within the context (and implementation) of each relevant action or commitment.

Mainstreaming of equality into strategies such as this is essential to drive lasting improvement. Policy makers may wish to refer to the guidelines on anti-racist policy making within ‘Anti-Racist Policy Making: Lessons from the first 20 years of Scottish devolution’.

**Regarding the understanding of governance**

Developing a good understanding of governance is an essential part of ensuring effective engagement between both service users and providers and sector professionals and policy makers.

Improving health and social care professionals’ understanding of governance and the importance of data for decision making can help ensure proper and responsible data collection. This, in turn, enables service users to be better informed about how exactly their data is used and why its collection is important.

This is particularly important when engaging with groups and individuals who may be more likely to feel hesitant towards providing additional identifiers and information deemed too personal or situationally irrelevant due to systemic inequalities and historic injustice.

A good, accessible and promptly available evidence base is essential for improving trust between health and social care providers and the general public. However, during the first waves of the COVID-19 pandemic, trust between the health and social care sector some Black and minority ethnic communities was damaged by a lack of information, data and answers on the disparate risk of COVID between ethnic groups.

Every effort should be made to rebuild this trust, ensuring that inequalities are identified, reported on and addressed and that everyone has reliable access to the health and social care data that might affect them. To maximise the accessibility of this data, standardised forms of data collection and presentation should be used, ideally shared across other key sectors, for improved comparability and familiarity. Where possible, systems should also be in place to minimise and mitigate potential language barriers to accessing health and social care data services, ensuring that all groups have equal access to their data.

Such changes would benefit service users by improving system transparency and contextualising their health and social care pathways, and third-party researchers, like CRER, by providing robust and timely evidence bases for academic, policy and other strategic work.

**Thinking about improving the quality of data that is used by health and social care services**

There are significant problems in the quality, availability and accessibility of equalities data within Scottish health and social care services. One way of improving the availability of data is emphasising and restating the importance of equalities monitoring – it should be understood as mandatory and essential, rather than a tacked-on service engagement exercise. For example, the collection of ethnicity data within health and social care services must be treated as importantly as the collection of age and sex information as key characteristics.

The quality and accessibility of data can also be improved using uniform data collection and publishing standards. For example, when collecting ethnicity information, ensure that it is collected in a disaggregated format under the same categories used by the Scottish census to improve comparability and facilitate effective monitoring and quantitative analysis.

Wherever this information is collected, it must also be used to further disaggregate information within the dataset to provide any kind of evidence on equality issues. For example, the Inpatient Census provides an ethnicity breakdown of respondents but doesn’t disaggregate its findings and corresponding data tables by ethnicity, making it useless for understanding and tackling inequalities relating to health and the healthcare sector.

In some instances, it may be argued that low numbers would make robust analysis impossible and jeopardise the anonymity of datasets but alternatives to mitigate this need to be sought and introduced, for example, data pooling over numerous years. Further, to ensure the accuracy and usefulness of health and social care data, it must be analysed and published in a timely manner and ideally presented on central public platforms, like NHS Scotland websites and, where relevant, the Equality Evidence Finder and the Race Equality Observatory evidence base.

CRER has a longstanding track record of campaigning for higher data standards throughout Scotland’s public sector, calling for the strengthened availability of data disaggregated by ethnicity and regularly publishing recommendations on how to address data gaps and scarcity from an equalities standpoint. Recently, CRER has been directly involved in the collection, analysis and dissemination of robust and high-quality healthcare data through our participation in the Expert Reference Group on COVID-19 and Ethnicity and social care data via the Scottish Government Cross Justice Group on Race Data and Evidence.

Going forward, CRER will continue to work towards minimising data scarcity and campaign for more accessible and higher quality data throughout the health and social care sector.

Health and social care workers need data on structural racism to better understand and tackle poor and unequal health and social outcomes across Scotland. However, data scarcity and systemic knowledge gaps significantly impede their ability to deliver the best services and devise effective policy and strategy.

To address this, service providers must be made aware of structural inequalities, their role within them, and how they can best be tackled through targeted training programmes, such as anti-racist training.

This requires dedicated anti-racist data collection initiatives to facilitate an accurate and well-maintained evidence base on the linkages between structural racism and health and social care outcomes – this could be built upon the systems proposed by the Scottish Health and Ethnicity Linkage Study (SHELS) or the census-linked Admin-based Ethnicity Statistics for England.

Building such an evidence base would require up-to-date census baseline population data, census data on long-term health conditions, disability and carer status, data on factors correlated with health outcomes, for example poverty (SIMD/Family Resources Survey), housing quality, health risking behaviours (smoking, excessive alcohol consumption, drug use), obesity and physical activity. Wherever possible, this data should be localised to the service provision area and disaggregated by protected characteristics, with the possibility of intersectional analysis.

To facilitate the availability of this data, Scottish Government or Public Health Scotland would likely need to commission the production of specific datasets from National Records of Scotland and other data holders, improving the level of detail over existing published datasets.

With this data available, health and social care professionals will have both improved understandings of systemic issues and the capacity to more effectively tackle unique structural challenges affecting marginalised and under-supported groups within their sector.

**We have heard that a more consistent approach to data standards will help improve insight and outcomes for individuals**

Agreed. Due to the sensitive and confidential nature of health and social care information, it is essential for any data made available beyond internal systems to be securely anonymised, with Scottish Government mandating and enforcing the standards for disaggregation to ensure data is thoroughly de-identified.

Additionally, standards must be set to improve the accessibility and reliability of public datasets to maximise the comparability, validity and timeliness of evidence bases, enabling more effective policy progress checking and cross-sector collaboration and data-linkage.

From an equalities standpoint within the health and social care sector, data standards must ensure that ethnicity data is collected at a disaggregated level in line with the categories used by the Scottish census, allowing for future data linkage and presenting the most complete picture of health outcome variation in Scotland.

Scottish Government should also ensure that datasets using public health and social care data are made available on a central platform to improve their accessibility, help avoid unnecessary duplications, and save time for service users and providers and third-party researchers seeking to use the data.

**When considering the sharing of data across Scotland’s health and social care system**

Publicly available health and social care data should be thoroughly and securely anonymised, likely via aggregation, and available at a local authority, council ward or Health Board area level. Where sample sizes are too small to ensure thorough anonymisation via aggregation at a local authority level, data should be pooled by grouping years.

Once any health and social care data has been processed, it should be made publicly available on a central platform to improve ease of access and remove barriers for small organisations and independent researchers who may utilise population-level health and social care information.

For CRER, there are two primary data needs and gaps. First, health and social care data incorporating ethnicity information is often unavailable in disaggregated forms, if collected at all. This can obscure key differences between individual ethnic groups, undermining stakeholders and decision-makers' capacity to understand and effectively challenge racial inequalities in health and social care outcomes. Second, data must be made available in as timely a manner as possible to enable effective progress checking and improve the accuracy and relevance of research analysis.

**Used appropriately and well, technologies such as Artificial Intelligence can help to improve decision making, empower health workers and delivery higher quality health and social care services to citizens, improving how you receive health and social care services**

As highlighted by a breadth of literature, traditional artificial intelligence development and training methods can often entrench bias and prejudice within AI systems, negatively impacting Black and minority ethnic groups and, in particular, BME women. If AI is to be incorporated into health and social care decision making processes, every precaution must be taken to ensure that biases within the training, deployment and evaluation process are identified and eliminated. Prior to AI systems being deployed within health and social care settings, AI infrastructure must be thoroughly vetted and assessed for bias by specialist groups to ensure they do not perpetuate structural inequalities that may exist in the systems informing them. Post-rollout, systems must be in place to monitor and regularly evaluate AI behaviour and performance over time, ensuring that biases do not emerge in the long-term. Overall Reflections 15 Please use this box to provide any further information that you think would be useful, which is not already covered in your response. Text Box (Multiple Lines): About you What is your name? Name: Lucien Staddon Foster What is your email address? Email: lucien@crer.org.uk Are you responding as an individual or an organisation? Organisation What is your organisation? Organisation: Coalition for Racial Equality and Rights (CRER) If answering for an organisation, from which sector is your organisation? third sector The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference: Publish response with name We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise? Yes I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy. I consent Evaluation Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.) Matrix 1 - How satisfied were you with this consultation?: Slightly satisfied Please enter comments here.: The Data Strategy for Health and Social Care demonstrates a positive shift in how Scottish Government treats and works with data and evidence. However, given Scotland-wide commitments to tackling inequality, CRER believes that increased attention should have been given to this within the Strategy, particularly due to the significant equality data scarcity issues within the Health and Social Care sector. While there are concurrent projects working with equality data, such as the Equality Evidence Strategy, commitments to improving the availability and quality of equalities evidence must be mainstreamed throughout all aspects of policymaking.