

# Response ID ANON-5A7J-EABM-C

Submitted to Consultation on Standards for Ethnicity Data  
Submitted on 2022-08-23 15:26:17

## Introduction

1 What is your name?

Name:  
Chris Carrigan

2 What is your email address?

Email:  
chris@usemydata.org.uk

3 What is your organisation?

Organisation:  
use MY data

4 If you collect, analyse or report on ethnicity data, please tell us about it here.

Please give details below:

use MY data is a movement of patients, relatives and carers, all with an interest in the usage of patient data to drive research, improve outcomes and reduce inequality. We do not hold any data.

## Proposal 1

5 Do you agree or disagree that we should publish this version of the Standards for Ethnicity Data?

Agree, this version should be published

## Proposal 2

7 Do you agree or disagree with our proposal for monitoring the use and impact of the Standards for Ethnicity Data?

Agree

## Proposal 3

9 Do you agree or disagree with us producing standards for data on other groups of people?

Agree

## Other comments

11 Is there anything else you would like to tell us about the Standards for Ethnicity Data?

Please give details below:

There are significant opportunities for data linkage, so that ethnicity data from one dataset can be used to supplement a different dataset which does not have ethnicity recorded. Technically, this should be relatively straightforward and could bring significant benefit to insights.

However, such linkages should NOT be seen as technical projects. The support of the public, and the success of the work, is far more dependent on ensuring there is openness and transparency about the intended outcomes, the proposed approach and the controls and governance over such linkages. As a movement of patients, relatives and carers, involvement of citizens from the outset is essential.

We have developed several Position Statements, all designed and agreed by our Members (patients, relatives and carers) which you might find useful:

Our expectations of organisations which use our data

<https://usemydata.org/resources/1%20-%20Expectations%20of%20organisations%20which%20use%20our%20patient%20data%20-%2026082021%20-%20final.pdf>

Our Transparency Principles

[https://usemydata.org/page\\_db.php?page=Transparency](https://usemydata.org/page_db.php?page=Transparency)

Highlighting the benefits of using patient data

<https://usemydata.org/resources/5%20-%20Highlighting%20the%20benefits%20of%20using%20patient%20data%20not%20just%20the%20risks%20-%2026082021>

Recognising the use of patient data

<https://usemydata.org/resources/6%20-%20Recognising%20the%20use%20of%20Patient%20data%20-%2027082021%20-%20final.pdf>