

Response ID ANON-CWNW-U146-F

Submitted to **UK Statistics Authority Inclusive Data Consultation**

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About you

What is your name?

What is your name?:

Rachael McKeown

What is your email address?

What is your email address?:

rachael@youngpeopleshealth.org.uk

Are you answering on behalf of an organisation or as an individual?

Organisation (please specify)

Are you answering on behalf of an organisation or as an individual?:

Association for Young People's Health (AYPH)

If you are answering on behalf of an organisation, what sector do you work in? This will assist us in monitoring the range of people that have responded to this survey.

Charity and voluntary

If you are answering on behalf of an organisation, what sector do you work in? (other):

What is the name of the organisation that you represent?

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Association for Young People's Health (AYPH)

We may wish to contact you in relation to your response or to invite you to attend follow-up events. Would you be happy for us to do so?

Yes

What is your main area of interest or your broad area of research, in terms of topic and groups that you're interested in?

What is your main area of interest or your broad area of research, in terms of topic/theme, groups that you're interested in, geographical and other coverage? :

Young people's health

To support transparency in our decision-making process, responses to this consultation will be made public. This will include the name of the responding organisation or individual. Please confirm that you are content for your name to be published. We won't publish personal contact details.

Yes, I consent to my name being published with my response

Current Data or Evidence

Are there any questions you are currently unable to answer because of a lack of data or evidence? If there are any, please tell us what they are.

What are the key questions you are currently unable to answer due to a lack of available data or evidence?:

AYPH publishes Key Data on a biennial basis, a report collating all publicly available data on young people's health in the UK. Through compiling the report, we have a sound understanding of data availability relating to the age group we are interested in (10-24), specifically healthcare and demographic / population statistics. However, the report can only present data within the public sphere and so there are a number of gaps in our understanding and unanswered questions. We don't know what we don't know, as certain data are not collected and reported.

We are often unable to answer questions in a satisfactory way due to the ways in which current data are presented – notably in inappropriate age bandings. This relates to a general inconsistency in definitions of a 'child' or 'young person' within agencies and organisations. Too often data are reported in inconsistent age bands, which makes comparison between age groups impossible. Alternatively, young people are grouped into large bands (e.g. 0-18 or 16-24), which obscures

nuances between different age groups. We recommend all data are reported in quinary age bands (0-4, 5-9, 10-14, etc).

Furthermore, we are currently unable to answer questions relating to health inequalities due to lack of data availability on health outcomes for different sub-groups of young people. Only certain data sources contain information on deprivation and ethnicity. Data on the experiences of specific groups of young people (e.g. young carers / LGBTQ+ young people / young travellers etc) are not routinely collected within healthcare statistics and so data collected is often via self-reported one-off surveys or qualitative findings. Without robust data on specific groups, we are unable to provide a comparison against the general experiences of young people and so services and policies cannot be planned to meet their specific needs. We recommend data routinely captures protected characteristics.

There are often data lags in data reporting, meaning that published data are not 'live' and cannot truly inform answers to current questions and problems. Additionally, we are often reliant on large datasets that have not been updated for many years (e.g. census data).

Please tell us the reasons why you are unable to answer these questions. (Please provide further details below)

Gaps in the current data?, Problems with measurement?, The level of detail available?

Please tell us the reasons you are unable to answer these questions. Is it because of::

Data and Evidence Accessibility

Are you currently able to access the data you need for your purposes?

Yes, some of it

If you are not able to access all the data or evidence you need for your purposes, what data are you unable to access and what are the barriers to you accessing this data?

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As outlined above, there are barriers in accessing data by appropriate age bandings and sub-groups relevant to young people.

Small charities and organisations may not have adequate resourcing to request data modifications to publicly available data – there may be data access charges and the process may be timely. Similarly, FOI requests are resource intensive processes.

Are there any issues with how the data or evidence that you currently rely on are presented? If so, please provide details.

10. Are there any issues with how the data or evidence that you currently rely on are presented? If so, please provide details.:

Data is often presented in inappropriate age bandings for children and young people.

Making Improvements

Thinking of all the issues you may have experienced with the data and evidence, which of the following improvements would you like to see? Please provide details.

Improve the level of detail available?

Thinking of all the issues you may have experienced with the data and evidence, what improvements would you like to see to::

Improved age bandings and more detail on sub-groups of young people.

Please tell us about how important it is for your purposes that data or evidence are comparable across different geographies, for example, across the 4 countries of the UK, internationally or at a more local level? Please give details of what geographies you would like to be able to compare across.

How important is it for your purposes that data or evidence are comparable across different geographies, for example, across the 4 countries of the UK, internationally or at a more local level? Please also tell us about any impacts you've experienced due to a lack of comparable data or evidence.:

There are difficulties comparing data across the UK's four nations. Data is often collected and reported differently, with slightly different definitions used and/or questions asked that reflect different research and policy contexts in each of the settings. Frequently, data for England and Wales is combined within healthcare statistics when it is most beneficial seeing the differences between the two countries.

It is important to be analyse data at regional and local levels. However, boundaries within England (and the UK more widely) are complex and reported differently across different settings and agencies. For example, in England there are Local Authority boundaries (with super local authority output areas) and NHS boundaries (with differing Clinical Commissioning Group footprints, STP / ICS boundaries, Trust locations and Primary Care Networks). These are further complicated when looking at other UK nations, with Health and Social Care Partnerships and Local Health Boards. Differences in the reporting of the exact 'locality' of each place can make comparing data from different agencies difficult (e.g. social care statistics against healthcare statistics).

Please tell us about any impacts you've experienced due to a lack of comparable data or evidence.

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What change to the current data or evidence would you most like to see to be able to answer the questions that are most relevant to you?

13. What change to the current data or evidence would you most like to see to be able to answer the questions that are most relevant to you?:

Improved age bandings and more detail on sub-groups of young people.

Please tell us about any examples of inclusive data and evidence that you think work well. If relevant, please include a link.

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If there is anything else you would like to add that hasn't already been covered, please share your views here.

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