



Here for young people
Here for communities
Here for you

THE CENTRE FOR YOUTH IMPACT

PART OF YMCA ENGLAND & WALES

Demographic data standard

V1.0

July 2025



Department
for Culture
Media & Sport

Everyone should have a fair chance to discover who they are and what they can become.

About YMCA

YMCA believes in fairness and opportunity. There are essential building blocks for a full and rewarding life: a safe home; acceptance; guidance; friendship; physical and mental health; academic support; employment skills; and access to real opportunities. Many young people have never known these things; other people have lost one or more as they grew up, but we all need them. All of us. At YMCA, we provide these critical foundations for a fresh, strong start for young people and a better quality of life in the community.

This content was developed by the Centre for Youth Impact, part of YMCA England & Wales, with the support of a range of funders, including the Department for Culture, Media and Sport (DCMS), Paul Hamlyn Foundation and Esmée Fairbairn Foundation.

The contents and resources are made free and accessible under the terms of the Creative Commons [CC BY-NC-ND 4.0](https://creativecommons.org/licenses/by-nc-nd/4.0/) licence. Please review the terms before using or sharing.

The Creative Commons CC BY-NC-ND licence enables you to copy and distribute the material in any medium or format in unadapted form only, for non-commercial purposes only, and only so long as attribution is given to the Centre for Youth Impact at YMCA England & Wales.

BY: Credit must be given to the creator of the material

NC: Only non-commercial uses of the material are permitted

ND: No derivatives or adaptations of the work are permitted

Table of Contents

<i>Development of the Data Standard</i>	5
Background	5
Overview.....	6
Ethical considerations	7
Design phase	7
Data collection phase	8
Data analysis, writing and communication phase	10
Safeguarding	11
<i>The Data Standard</i>	14
Appendix 1: Demographic Data collection	29

Development of the Data Standard

Background

This data standard was developed by the Centre for Youth Impact at YMCA George Williams College (now part of YMCA England & Wales), in collaboration with the Back Youth Alliance and the Department for Culture, Media and Sport (DCMS), in order to promote alignment in the collection of demographic data about the young people accessing and engaging in informal and non-formal youth provision. This, in turn, aimed to facilitate the collation of shared data to enable a coherent message about the reach of provision and the context for its value in the lives of young people.

As part of its work supported by DCMS, the Centre for Youth Impact at YMCA George Williams College had both the ambition and remit to bring youth sector organisations together to build a collective approach to gathering, storing and analysing data to inform shared understanding and messaging about the reach, quality and impact of youth provision. This ambition aligned with the Back Youth Alliance's¹ priority goal to present shared data to strengthen the voice of the youth sector organisations. As such, the College worked with Back Youth Alliance members between 2022 and 2025 to scope and develop an approach to shared data, and subsequently expanded its work to include a wider collective of youth sector infrastructure and delivery organisations, funders and research experts, through the Youth Work Evidence Alliance, to build greater consensus and alignment across the sector.

This development of this data standard has been an iterative process, drawing on existing data formats as far as possible. The intention was to align with national data sets, whilst considering their applicability in collecting data from young people in open access youth work and informal/non-formal learning settings, alongside young people's perspectives of (potentially sensitive) personal data collection. Regardless, this data standard should still be considered to be in its beta stage, whilst it is being tested. Further iterations will be published openly.

¹ The Back Youth Alliance is comprised of ten national youth organisations working together to influence support and funding for the benefit of all young people and the organisations that support them. Members include British Youth Council, Duke of Edinburgh's Award, Girlguiding, National Youth Agency, OnSide, The King's Trust, Scouts, UK Youth, YMCA England & Wales, and Youth United Foundation.

Overview

Alongside shared measures (that is, common approaches to measuring the quality of provision and changes in outcomes for young people), data standards are foundational in supporting a collective approach to gathering, storing and analysing data to inform shared understanding and messaging about the reach, quality and impact of youth provision.

A 'data standard' is an agreement on the representation, format and definition for common data. This 'common data' could be anything, from how a postcode is recorded (for example, the first element only – BS1 or EC1M – rather than a full postcode – BS1 6BX or EC1M 6EH) to the format for recording people's names (for example, the first initial only, or whether to include any middle names) to an agreed way of recording levels of satisfaction in customer feedback.

A data standard is not the same as a quality standard. A quality standard tends to refer to a benchmark that is pre-determined as 'good', and which needs to be reached, potentially as part of a regulatory or compliance regime. Organisations are encouraged to work towards and meet these standards as a proxy for delivering good or effective practice. Examples include the [NYA Quality Mark](#) and [NCVO's Trusted Standard](#).

A data standard simply refers to a 'standard' way of doing things. Data standards make it easier to publish, share, access and use better quality data. Adopting data standards in the youth sector will enable us to build insights into, and communicate, *which* groups or communities of young people are engaging in *what* provision, *how* they are engaging, and the *impact* on their lives. Conversely, it will also allow us to better understand which young people are *not* being reached or engaged equitably.

Publishing or proposing a data standard does not mean that everyone has to collect this data. It simply proposes a) an agreed way of collecting this data where it is already being collected, and b) a route in for organisations that are not already collecting this data. Similarly, a data standard does not always mean every element has to be used. It may not be desirable, feasible or even useful in some settings to share personally identifiable data. It may be useful in other settings to collect some, but not all, elements of demographic data. However, a data standard will still be useful in circumstances where organisations could aggregate their data (for example, to understand the gender balance across provision in a particular region, or where a named Fund wishes to build insight into the proportion of young people with SEND accessing services) or where there is an identified need to link data across a multi-agency project, and the appropriate

data sharing agreements and consents are in place to facilitate this. This standard has therefore been drafted to cover the most common types of demographic data collected.

Ethical considerations

Having a common, core set of demographic data is a key part of supporting the youth sector to access shared data that enables it to powerfully describe its reach, alongside building insight into accessibility and inclusion. However, any plans or intent to collect data should be considered in the context of:

- whether the specific data being collected brings benefits to the organisation, young people and/or wider public;
- the organisation's capacity to ethically and securely collect, store, share and destroy the data; and
- whether the organisation has the capacity and resources to effectively use the data and in particular to follow up on any safeguarding concerns that may arise from responses.

These guidelines should be considered in relation to individual youth organisations' ethical principles, and the UK GDPR as well the Equality Act 2010². Evaluation and research activities in youth provision are informed by a set of research ethics in just the same way as youth work practice is informed by youth work ethics (NYA, 2022). Please also consider reading the [government guidelines on collecting demographic data](#) and the [British Educational Research Association](#) ethical guidelines.

The ethical considerations apply to the three phases addressed below: design phase; data collection phase; and data analysis, writing and communication phase

Design phase

Age, disability, gender reassignment, sex, marriage and civil partnership status, race, religion and belief, pregnancy and maternity, and sexual orientation are protected characteristics under equality law. Some agencies also now treat care experience as a protected characteristic. In addition, and in consultation with members of the Back Youth Alliance, asylum seeking status and geographical location are included within demographic characteristics as part of this data standard. It is recognised there are ethical considerations to collecting this data, and the specific considerations for certain items have been highlighted. However, the following are overarching principles that are critical to consider in advance:

- How will the data be used to influence service provision?
- Who is the demographic data for, and how will it be shared with different audiences?

² Equality Act 2010: <https://www.equalityhumanrights.com/equality/equality-act-2010>

- Is there any public value in obtaining this demographic data?
- How and when will data be gathered from young people, and what depth of relationship needs to exist between the young person, the practitioner and wider youth organisation to support this?
- Does the organisation have capability and capacity to securely store and analyse the demographic data, and manage any safeguarding concerns arising from responses received?
- Could collecting demographic data on certain protected characteristics, such as sexual orientation, sex, and/or gender, impact on young people's perception of the provision or even discourage or prevent them from engaging? How will this be managed?
- Could collecting any specific aspects of demographic data put young people in a vulnerable position?

As demographic data is likely to be used to determine whether certain groups or communities of young people are accessing provision, and/or to improve and tailor provision for such groups, specific elements of the data standard should be selected on that basis. Only data that is going to be used should be collected. However, it is important to note that 'we won't use that data' and 'we don't have young people like that in our provision' are *not* the same thing. A youth organisation that tends to attract mainly white British young people to open access provision *should*, in fact, gather data on ethnicity to enable it to explore why other communities aren't engaging – and to test their assumptions. It is not sufficient to overlook this part of the data standard on the grounds that 'all our young people are white', or 'we work in a very white area'.

This data standard has been designed to align with good practice guidance in:

- allowing young people to say they don't know the answer or that they would prefer not to answer individual questions;
- offering multi-select checkboxes so young people can select all the terms or options that resonate with them;
- ordering responses in alphabetical order to avoid any implication of bias and 'othering' (youth organisations should consider their 'defaults' in how data options are presented, including whether they reflect diversity and inclusion values);
- using appropriate wording and allowing young people to self-describe in their own words; and
- ensuring clarity on what organisations will do with the data.

Data collection phase

At the start of and throughout data collection, youth organisations should consider how they will:

- make it clear to the young person what practitioners/the organisation intend to do with their data;

- explain the organisation's privacy policy so that it is accessible to *all* young people;
- ensure ongoing informed consent from young people (and parents/carers as necessary);
- maintain a clear focus on ensuring the rights and dignity of the young people at the heart of the data collection process;
- respect young people's right to decline to participate (and withdraw at a later stage), including not requiring a response to any particular question;
- structure and present data collection processes so that they are accessible to all young people;
- be ready to respond to or manage any emotions or safeguarding concerns that the data collection triggers; and
- enable young people to feedback on the data collection wording and process to support continuous improvement.

Informed consent

When collecting demographic information and/or data on protected characteristics that may identify a young person, it is important to have informed consent. Young people may be identified through data collection even if their names and dates of birth are not collected. In a small group or cohort, it may be possible to identify individual young people through collecting other pieces of data about ethnicity or disability, for example.

If the young person is under 16, it is advised to gain the written consent of the parent/guardian *and* the verbal consent of the young person prior to collecting any data. Consent could be gained by sending a link to an information sheet and consent form, or by chatting through the purpose of the data collection with the parent/guardian and giving them a short consent form to sign. Young people and parent/guardians should be made aware of how their personal data is intended to be stored, shared, used and destroyed. This is especially pertinent in instances where protected characteristics relate to, for example, gender, gender reassignment, ethnicity or asylum-seeking status, which may be associated with such stigma or mistrust that young people and parents/guardians are cautious when sharing this data. The information should be presented in such a way as to be understandable and accessible to the person giving consent.

If the young person is 16 or over, they can consent themselves, but it should be 'informed' consent. There may be circumstances where the young person does not have the capacity to provide informed consent to collect, store and share their personal data. If there is doubt, a parent/guardian/supporting adult may be able to advise or, if necessary, give their consent alongside the young person's.

In instances where English is not the first language of the young person and/or their parent/guardian, consent may need to be obtained in another language.

The power dynamics between the practitioner, young person and/or parent/guardian should also be considered when obtaining consent, particularly if the young person or their parent/carer is vulnerable (including due to mental health conditions, disabilities, migrant status, involvement in the criminal justice system etc.). Here practitioners should be mindful of full comprehension, and the potential for consent under perceived duress or the potential to feel coerced into giving consent.

Organisations should also ensure the parent/guardian and/or the young person are given the opportunity to withdraw the young person's personal data at any time and that the organisation has the capability and capacity to fulfil this ethical obligation.

Collecting and recording demographic data

Consent must be approached with respect and dignity *before* collecting demographic data from young people. Youth organisations should ensure that practitioners have the time, confidence and knowledge to answer questions that may arise, such as how young people's personal data will be used, stored, shared and destroyed, and whether there are any consequences should a young person decline to take part. Practitioners will need to have established a rapport with the young person. The practitioner should also be cognisant of the power dynamics throughout the data collection process and support the young person to feel safe and empowered to answer as they wish.

Data analysis, writing and communication phase

Ethical considerations - how the data is analysed, presented and communicated - relate to thinking about the quality and integrity of the data, the purpose of the data, and how it is shared.

Who is accessing provision

Demographic data can be analysed and interpreted to determine which groups or communities of young people are accessing provision (or not). It may also be useful to explore *how* different groups are accessing provision (for example, frequency, or engaging in a certain type of provision such as group versus one to one).

Youth organisations should consider who will have access to these findings: internal staff and volunteers, young people, funders and/or the public, for example. Youth organisations should also consider whether they have the capacity and resources to adhere to GDPR and ethical standards of collecting and storing demographic data (see the below sections on data collection and data storage).

Improving and tailoring provision

It is suggested caution is exercised when comparing, for example, outcomes data across different groups. It is important to consider other influences on different (sub)groups that

are outside of the provision context. This is part of the critical importance of understanding young people's context and environment. Equally, provision may have been tailored for different groups of young people, and this should be taken into account if there is a plan to compare outcome data across groups.

There is a recognition of the need to be mindful and sensitive to the stigma associated with certain protected characteristics when publishing findings in relation to protected characteristics³.

Transporting and storing demographic data

It is recommended that written consent and young people's demographic data is 'transported' securely, not left unsupervised and is stored securely; for example, in a locked cabinet. This includes both electronic and hard copy data. Once demographic data is recorded electronically, it is recommended the paper version be destroyed securely. In instances when entering young people's data on an electronic system (for example, Excel), ensure that young people's responses are stored in a separate file to their personal information (for example: name, age, gender, ethnicity, address etc). Files that *do* contain personal information (for example: name, age, gender, ethnicity, address etc) should be stored on a secure server in a password protected file.

Destroying demographic data

It is recommended that each organisation sets a time limit for destroying demographic data. This should be set considering the period over which a young person is accessing provision and whether there is a need to retain records for safeguarding purposes. Electronic demographic data should be destroyed securely from servers. Any paper-based demographic data should be destroyed using secure methods, such as secure bins that are sent to confidential sites for shredding.

Safeguarding

Whilst none of the items included in this demographic data standard directly address or ask about safeguarding issues, it is recognised that some young people may disclose information as part of the data gathering process, and/or an individual item may trigger or prompt particular issues for young people.

³ <https://medium.com/managing-on-the-margins/respectful-collection-of-demographic-data-56de9fcb80e2>

It is recommended that organisations build their GDPR policies and guidelines in and around their existing safeguarding policies and structures to reduce any friction or obstacles to good practice.

Below are some areas to consider:

1. Be clear about safeguarding in data policies

When developing any data collection policies or privacy notices, be transparent as to the conditions or circumstances under which any information might be shared. Ensure young people know where they can seek any additional support, in confidence, if they wish to. This should include internal and external channels of support.

2. Consider whether to seek consent for sharing information *after* disclosure

Whilst organisational policies may make clear safeguarding practices prior to any information being disclosed, in general youth organisations should seek consent *after* any disclosure to share such information. However, in some instances it may not always be safe or appropriate to seek consent, and youth organisations may consider sharing information even if consent has been explicitly denied. Under the GDPR and Data Protection Act 2018, youth organisations may share information *without* consent if, in their judgement, there is a lawful basis to do so, such as where safety may be at risk. Such judgements will be case-specific depending on the facts and factors involved.

3. In in doubt, seek advice from experts

Clearly explain the case without disclosing the identity of the individual where possible. Double checking is always a much safer option before progressing. The first point of call should be the organisation's Safeguarding Lead.

4. Consider safety and well-being

Any safeguarding decisions should be informed by consideration of the safety and wellbeing of the individual and others who may be affected. This may include public safety.

5. If sharing information, follow GDPR guidelines

Any information shared should be necessary, proportionate, relevant, accurate, timely and should be shared securely, and is shared only with those individuals who need to have it.

6. Document decisions and store this securely

Youth organisations should keep a record of their decisions in relation to data sharing, what informed them, how they were informed, and the reasons for it.

- a. If organisations decide to share any information, then record what has been shared, with whom and for what purpose. Keep information factual, detailed, accurate and up to date.
- b. If organisations do not decide to share information, record why this course of action was deemed the most appropriate.

7. Set data retention periods for stored data

It can be difficult to put a retention timeframe on safeguarding data, and there is no set term in law. Some agencies, for example in the education and health sectors, have their own guidance for the retention of child protection information. A useful general principle in England, Scotland and Wales is that the file should be kept until the child is 25 (this is seven years after they reach the school leaving age)⁴.

8. Security and Privacy

Youth organisations must put in place appropriate security for their data. Organisations must ensure access controls on safeguarding information are very tight, control who and how many persons have access to the information, and consider which devices the data is being accessed on. It is always preferable to have fewer staff and fewer devices where access is possible.

⁴ Information & Records Management Society, 2019, p. 93

The Data Standard

The format for collecting data is outlined with guidance notes provided for young people or their parents/carers completing the data collection. There are also explanatory notes in italics to share the information considered, and the rationale of the Back Youth Alliance organisations, in developing the standard. Where the Standard draws on existing data standards or data sets, a source note with links has been provided. A version of the standard for data collection is provided in Appendix 1.

1. Name

First name
Last Name
Preferred name

Notes: *Organisations may collect this for their own records. It is not intended for sharing.*

2. Date of Birth

DD-MON-YYYY

Notes: *This is useful for sharing to indicate the ages organisations/the wider sector is working with and to calculate equivalence in school years. Organisations can still collect date of birth individually as DD- MM-YYYY but at the point of sharing, it would be translated to DD-MON-YYYY to avoid confusion with international data sets.*

3. Address

Property Number or Name
Street or Road Name
Village/town
Town/City
County
Postcode

Guidance: Postcodes should always be in BLOCK CAPITALS with no punctuation or spaces between the two parts of the postcode to reduce data entry errors.

Source: <https://www.mrs.org.uk/pdf/postcodeformat.pdf>

Notes: *Postcodes are useful for sharing especially as links to understanding of deprivation. If they are collected in a user-determined format, they should be reformatted as per the guidance prior to sharing.*

4. Sex

Female
Intersex
Male

Guidance: Sex is recorded at birth through our visible bodily differences. Clarity is achieved when needed through looking at

hormones or internal physiology. There are three sexes: male, female and intersex. Intersex people are born with sex characteristics (including genitals, gonads and

chromosome patterns) that do not fit typical binary notions of male or female bodies. Intersex is an umbrella term used to describe a wide range of natural bodily variations.

If you're not sure how to answer, use the sex registered on your official documents, or whichever sex you consider yourself to be.

Source : <https://www.bsuh.nhs.uk/wp-content/uploads/sites/5/2016/09/Gender-and-Sexual-Diversities-Briefing.pdf>,
<https://www.ons.gov.uk/census/censustransformationprogramme/questiondevelopment/genderidentity/guidanceforquestionsonsexgenderidentityandsexualorientationforthe2019censusrehearsalforthe2021census#:~:text=transgender%20male,non%2Dbinary>

"Free & Equal Campaign Fact Sheet: Intersex" (PDF). United Nations Office of the High Commissioner for Human Rights. 2015.

***Notes:** Government guidance recommends using 'sex' when biological data is needed (for example, when providing a medical service), otherwise use 'gender'. The general consensus of the BYA was that most members would collect and share gender, as that would be more relevant to young people's self-identity, however for younger children, or where the parents would be answering, the sex question and part 2 of the gender question may be more appropriate.*

5. Gender

Which of the following terms best describes your current gender identity? We understand that there are many different ways you may identify, so please pick the one that best describes you:

Boy or man
Girl or woman
Nonbinary
I am not sure or questioning
I don't know what this question means
Prefer to self-describe [open text box]

Prefer not to say

Guidance: The Council of Europe defines gender identity as a person's deeply felt individual experience of gender, which may or may not correspond with the sex assigned at birth, and includes the personal sense of the body and other expressions of gender (that is "gender expression") such as dress, speech, and mannerisms.

Source: <https://www.thetrevorproject.org/wp-content/uploads/2021/07/Measuring-Youth-Sexual-Orientation-and-Gender-Identity.pdf> <https://www.surveymonkey.co.uk/curiosity/ask-survey-questions-sexual-orientation-gender-identity/>

Notes: *We have not included genderfluid and genderqueer because non-binary is by far the most selected category (beyond 'boy or man' and 'girl or woman'), and we have 'prefer to self-describe' as an option, but if an organisation wishes to provide those options they should do so as distinct categories.*

Notes: *In the Census, the gender identity question is voluntary and only asked of those aged 16 years and over. There were concerns about parents/carers filling it in for a child in a different way to which the child would wish.*

Part two may be used alongside part 1 to recognise trans young people or alongside the sex question if parents are likely to be answering on the young person's behalf.

Organisations may decide to only ask this if it is pertinent to the type of activity/provision they deliver. The government guidance is to only ask users about gender or sex if you genuinely cannot provide your service without this information. However the Office for National Statistics (ONS) have stated that it needs it "to support work on policy development and service provision and to further equality." The charity Stonewall notes that gathering data on gender identity and sexual orientation can support equality and inclusion sending a clear signal to LGBTQIA+ people that their experiences are taken seriously, and it enables you to respond to local need. It can also help with targeting programmes and activity to support a specific gender or sexual orientation. In this situation it is justified to ask SOGI (sexual orientation and gender identity) questions to understand and demonstrate the success of the programme or event, and uptake among the target group.

Source: https://www.stonewall.org.uk/sites/default/files/do_ask_do_tell_guide_2016.pdf

6. Sexual Orientation

Asexual
Bisexual
Gay
Lesbian
Pansexual
Queer
Straight/heterosexual
Prefer to self-describe [open text box]
Prefer not to say
Don't know or unsure

Source: <https://www.ons.gov.uk/census/censustransformationprogramme/questiondevelopment/census2021paperquestionnaires>

Notes: As with gender identity, collecting sexual orientation data can support inclusion and equity but it should be made clear why the information is being collected. BYA members considered that it was important to collect as sexual orientation data directly relates to young people's self-identity and outcomes (noting outcomes are often worse for young people who identify as LGBTQIA+) but it was also recognised that it may depend on age and was important to have the young person's self-identified sexual orientation rather than their parents'/carers' perspective. It was questioned whether contributing to a collective dataset was sufficient reason to collect the data even if not using it within the organisation; individual organisations would need to consider this factor.

We have proposed separating out Gay and Lesbian as they are two distinct identities and would be experienced differently.

7. Ethnicity

Asian or Asian British	Indian
	Pakistani
	Bangladeshi
	Chinese
	other Asian background
Black, Black British, Caribbean or African	Caribbean
	African
	Any other Black background, Black British or Caribbean background
Mixed or Multiple ethnic group	White and Black Caribbean
	White and Black African
	White and Asian
	Any other Mixed or Multiple background
White	English, Welsh, Scottish, Northern Irish or British
	Irish
	Gypsy or Irish Traveller
	Roma
	Any other White background
other ethnic group	Arab

	Any other ethnic group [if collecting electronically then dropdown box of option Sikh, Latin American, Kurdish, Other, Prefer to self-describe [open text box]]
Don't know	
Prefer not to say	

Source <https://www.ons.gov.uk/census/censustransformationprogramme/questiondevelopment/census2021paperquestionnaires>

<https://www.ethnicity-facts-figures.service.gov.uk/style-guide/ethnic-groups/>

Notes: The left-hand column can either be integrated with the right-hand column e.g. 'Asian or Asian British: Indian' or just used as a subheading to avoid three levels of 'other'

8. Religion

Buddhist
Any Christian denomination
Hindu
Jewish
Muslim
Sikh
Any other religion
No religion or agnostic
Don't know

Prefer not to say

Source

<https://www.ons.gov.uk/census/censustransformationprogramme/questiondevelopment/census2021paperquestionnaires>

Notes: Government guidance includes to consider collecting data on religion as this helps people to give details about their full cultural identity and improves the acceptability of the ethnicity question.

Source: <https://www.gov.uk/government/consultations/standards-for-ethnicity-data/standards-for-ethnicity-data>

9. Physical/health conditions and disability

Do you have any of the following?

- physical health conditions or illness (lifelong or lasting or expected to last 12 months or more, even if not continuous)
- mental health conditions or illness (lifelong or lasting or expected to last 12 months or more, even if not continuous)
- neurodiverse conditions
- None of the above
- Prefer not to say

[Depending on how the organisation intends to use the data to support a young person, there could be a follow up question to gather more details using the list below]

Long term pain

Chronic health condition

Mobility

Dexterity

Mental health
Visual
Breathing
Memory
Hearing
Learning
Speech
Behavioural
Other
Prefer not to say

Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry-out day-to-day activities?

Yes, a lot
Yes, a little
No, not at all

Source: <https://www.gov.uk/definition-of-disability-under-equality-act-2010>,
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/disabilityenglandandwales/census2021>

Notes: *If a respondent selects 'yes' to any of the first three options in question 1 and either 'yes a lot' or 'yes a little' to question 2 they are defined as being disabled in accordance with the Equality Act.*

Although the ONS asks the options in question 1 as an overall question it was noted that people who were neurodiverse may not connect with these descriptions, particularly with the time framing as neurodiversity is a lifelong condition. As neurodiversity is classed as a disability, separating it out still retains the ability to cross-reference to the wider ONS data. Generally, guidance advises

being clear on why you want the information, and what you will do with it to ensure young people feel confident to respond. It may be unhelpful to use the title of disability as it may influence how people think about the question

10. Care experience

Are you 'care experienced'? This includes, at any point in your life:

- living with foster carers
- living in a residential children's home
- being looked after at home under a supervision order
- living with friends or relatives in kinship care - either formally (arranged through the local authority or social services) or informally (arranged within the family)

Yes
No
Don't know
Prefer not to say

Notes: *Depending on the provision it may be relevant to ask an additional question on being estranged or homeless as this falls outside of 'care experienced'.*

The measure was considered important as it relates to lifelong outcomes however it was also noted that asking it could raise safeguarding concerns that the provider would then have a duty of care to respond to; capacity (in terms of time, skills or processes) to respond should therefore be a consideration of whether to ask the question.

Although DfE rejected the Independent Review of Children's Social Care's recommendation that care experience become a protected characteristic under equality law, the campaign has strong support and some local councils have passed motions pledging to treat care experience as a protected characteristic.

Source: <https://www.communitycare.co.uk/2023/02/07/dfe-care-review-response-key-points/#:~:text=The%20DfE%20will%20also%20consult,the%20independent%20reviewing%20officer%20role.>

<https://www.cypnow.co.uk/content/news/care-review-response-sector-appalled-at-failure-to-implement-protected-characteristic-recommendation/>

11. EET status

Which of the following best applies to you?

Education
I am at school, sixth form or enrolled on a course at college
I attend a Pupil Referral Unit, other alternative education provision or am home schooled
I am on the school roll but access education through another organisation e.g. a youth club
I am not on any school roll/ I am waiting for a school place/ I am self-excluding from education
I have left education and am actively seeking work
I have left education but I am not actively seeking work (due to caring responsibilities or health reasons, for example)
I have left education and am working
Prefer not to say

Please tick if any of the following apply to you

I am doing an apprenticeship (a paid job <i>with</i> hands-on work experience alongside off-the-job training)
I am on traineeship (a course with work experience that gets you ready for work or an apprenticeship- unpaid but you may get expenses paid)
I am in paid employment less than 16hrs per week
I am in paid employment more than 16hrs per week

Notes: It was recognised that not everyone will use all the options, but these were seen as the most helpful.

12. Young carers

Do you regularly provide unpaid care (not babysitting) for a relative, friend or family member with an illness, disability, mental health condition or a n addiction?

Yes
No
Don't know
Prefer not to say

Source:

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/articles/2011censusanalysisunpaidcareinenglandandwales2011andcomparisonwith2001/2013-02-15>

13. Asylum seeker or refugee status

Are you or have you ever been an asylum seeker or refugee?

Asylum seeker
Refugee
No
Don't know
Prefer not to say

Notes: *It is acknowledged that this can be a highly sensitive subject and for Asylum Seekers in particular there may be real or perceived risks in declaring their status - it is recommended therefore that this question is only asked if it directly relates to the targeting or content of the provision.*

Appendix 1: Demographic Data collection

1. Name

First name
Last Name
Preferred name

2. Date of Birth

DD-MON-YYYY

3. Address

Property Number or Name
Street or Road Name
Village/town

Town/City
County
Postcode

4. Sex

Female
Intersex
Male

Guidance: Sex is recorded at birth through our visible bodily differences. Clarity is achieved when needed through looking at hormones or internal physiology. There are three sexes: male, female and intersex. Intersex people are born with sex characteristics (including genitals, gonads and chromosome patterns) that do not fit typical binary notions of male or female bodies. Intersex is an umbrella term used to describe a wide range of natural bodily variations.

If you're not sure how to answer, use the sex registered on your official documents, such as passport or driving licence, or whichever sex you consider yourself to be.

5. Gender

a) Which of the following terms best describes your current gender identity? We understand that there are many different ways you may identify, please pick the one that best describes you:

Boy or man
Girl or woman
Nonbinary
I am not sure or questioning
I don't know what this question means
Prefer to self-describe [open text box]
Prefer not to say

Guidance: The Council of Europe defines gender identity as a person's deeply felt individual experience of gender, which may or may not correspond with the sex assigned at birth, and includes the personal sense of the body and other expressions of gender (that is "gender expression") such as dress, speech, and mannerisms.

a) _Is the gender you identify with the same as your sex registered at birth?

Yes
No
Don't know
Prefer not to say

6. Sexual Orientation

Asexual
Bisexual
Gay
Lesbian
Pansexual
Queer
Straight/heterosexual
Prefer to self describe [open text box]
Prefer not to say
Don't know or unsure

7. Ethnicity

Asian or Asian British	Indian
	Pakistani
	Bangladeshi
	Chinese
	other Asian background
	Caribbean

Black, Black British, Caribbean or African	African
	Any other Black background, Black British or Caribbean background
Mixed or Multiple ethnic group	White and Black Caribbean
	White and Black African
	White and Asian
	Any other Mixed or Multiple background
White	English, Welsh, Scottish, Northern Irish or British
	Irish
	Gypsy or Irish Traveller
	Roma
	Any other White background
other ethnic group	Arab
	Any other ethnic group [if collecting electronically then dropdown box of option Sikh, Latin American, Kurdish, Other, Prefer to self describe [open text box]]
Don't know	
Prefer not to say	

8. Religion

Buddhist
Any Christian denomination
Hindu
Jewish
Muslim
Sikh
Any other religion
no religion or agnostic
Don't know
Prefer not to say

9. Physical/health conditions and Disabilities

a) Do you have any of the following?

- Physical health conditions or illness (lifelong or lasting or expected to last 12 months or more, even if not continuous)
- Mental health conditions or illness (lifelong or lasting or expected to last 12 months or more, even if not continuous)
- Neurodiverse conditions
- None of the above
- Prefer not to say

[Depending on the intended use of the data, there could be a follow up question to gather more details]

Long term pain
Chronic health condition
Mobility
Dexterity
Mental health
Visual
Breathing
Memory
Hearing
Learning
Speech
Behavioural
Other
Prefer not to say

Does your condition or illness/ do any of your condition or illnesses reduce your ability to carry-out day-to-day activities?

Yes a lot
Yes a little
No not at all

10. Looked after Children

Are you 'care experienced'? This includes, at any point in your life:

- living with foster carers
- living in a residential children's home
- being looked after at home under a supervision order
- living with friends or relatives in kinship care - either formally (arranged through the local authority or social services)

or informally (arranged within the family)

Yes
No
Don't know
Prefer not to say

11. EET status

Which of the following best applies to you?

Education
I am at school, sixth form or enrolled on a course at college
I attend a Pupil Referral Unit, other alternative education provision or am home schooled
I am on the school roll but access education through another organisation e.g. a youth club
I am not on any school roll/ I am waiting for a school place/ I am self-excluding from education
I have left education and am actively seeking work
I have left education but I am not actively seeking work (due to caring responsibilities or health reasons, for example)
I have left education and am working
Prefer not to say

Please tick if any of the following apply to you:

I am doing an apprenticeship (a paid job <i>with</i> hands-on work experience alongside off-the-job training)

I am on traineeship (a course with work experience that gets you ready for work or an apprenticeship- unpaid but you may get expenses paid)
I am in paid employment less than 16hrs per week
I am in paid employment more than 16hrs per week

12. Young carers

Do you regularly provide unpaid care for a relative, friend or family member with an illness, disability, mental health condition or an addiction? (this does not include babysitting)

Yes
No
Don't know
Prefer not to say

13. Asylum seeker or refugee status

Are you or have you ever been an asylum seeker or refugee?

Asylum seeker
Refugee
No
Don't know