The Trans Learning Partnership

Data Practice Guidelines

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Introduction

This document provides information to support third sector organisations to gather, store and use data in line with best practice.

General information about data is initially shared. The rationale for collecting demographic data from the people we work with is then presented, followed by recommendations for the information that should be collected for each demographic characteristic and how that information should be collected. Ways to effectively gather service evaluation data are then discussed.

There are two accompanying resources to this guide:

- A model questionnaire demonstrating demographic data collection questions.

- A PDF which pictorially describes the suggested data collection practices recommended in this guide.

The information presented in this guide brings together learning and best practices from across the Trans Learning Partnership partner organisations, research, and advisory groups.

Comments and suggestions on the content of this guide are warmly received by the authors, who understand that data practices and terminology surrounding demographic data are ever changing, and that their interpretation of best practice is not universal.

This guide has been compiled by M.Wilkie and J.Blackledge.

Part 1: Data Basics

What is data?

- Data is information that is recorded, collected and stored. Data can take many forms, and does not refer exclusively to numerical information, or to information stored electronically.

What do we do with data?

- We collect it from our stakeholder groups as part of every-day activities.
- We store it (securely!)
- We maintain it – this means we run regular checks on our data to ensure it meets our quality, privacy, and ethical standards, investigate any anomalies, and ensure it is backed up
- We appraise it regularly to determine whether it is still needed or can be disposed of
- Use it for service improvement, community insight, and effectively evidencing funding reports and bids.

Why do we collect data?

- To have a means of identification for service users
- To understand who service users are and identify gaps in service provision
- To record information that helps to understand service user needs
- To continuously evaluate how well service user needs are met and adapt practice where necessary
- To demonstrate the impact of services
- To share information with stakeholders such as funders and policymakers when it's relevant and appropriate to do so
- To show accountability to the communities served to build trust. There can be power imbalances inherent in the service user/service provider dynamic and demonstration of accountability can mitigate the effects of this.

Data ethics

- When collecting any data it is necessary to consider if the information is needed, how it will be stored, and what the information should be used for. This can help reduce concerns around data safety.
- It's important that when we are trusted with data we treat it with care. We must also stick to the law when working with data. This means the data is:
    - Collected with consent from the data subject

  - Collected and used for specified and explicit purposes, meaning:
    - Data is not collected without a good reason
    - The reasons for data collection are understood by data subjects
  - Used fairly, lawfully, and transparently
  - Kept for no longer than necessary
  - Handled securely
  - Accurate and up to date
- Data collection practices should be accessible to those who need to use them:
  - Beware of introducing bias through exclusionary data collection practice. For example: only asking existing group attendees if the location of the group is accessible to them.
  - Have data collection instruments available in a variety of formats and/or languages, and collecting data via outreach if appropriate
  - Using clear language
  - Including “escape” options for multiple choice questions such as “Prefer not to answer” – reluctance to answer a question is still a data point.
  - If at all possible, offer material incentives for evaluative data collection (eg vouchers, prize draw)
  - Ensure data visualisation and reporting is accessible

Part 2: Collection Guidelines for Demographic Data

This section contains a brief overview of the *rationale* for collecting demographic data, recommendations for what information should be collected for each demographic characteristic, and recommendations for *how* that information should be collected.

Example questions for each demographic characteristic are included. These example questions are also presented in an example model questionnaire. This includes example guidance notes which should be adapted according to organisational need. Accompanying slides are also provided giving visual representation of this information, with each question clearly labelled with corresponding notes and callouts.

Please note that this resource ***does not*** offer guidance on information collection or handling in relation to safeguarding.

2.1 General Guidelines

Why do we collect demographic data?

1. To provide information to funders via reports and proposals

Common demographics requested by funders may be age, location, and whether the service user is part of a certain community (for example socioeconomic status or ethnic group). Collecting this data routinely allows funding reports to be efficiently evidenced and provides evidence for further funding bids. It also provides a means of showing accountability to the communities served, i.e. “we do what we say we will”. There can be power imbalances inherent in the service user/service provider dynamic, and demonstration of accountability can help mitigate the effects of this.

2. Service evaluation and improvement

Demographic and evaluative data collection can be used in tandem to understand service user needs and establish whether a service is accessible and welcoming to all users. It provides an evidence base for service improvement and adaptations, or for targeted service provision. It can also be used for future-proofing a service as trend-changes in demographics of new service users can be used for service planning. Furthermore, aggregated, anonymised data can be shared in service user reports to increase organisational transparency and explain any changes to service provision or strategic goals.

When should we collect demographic data?

Demographic data may be collected from all new service users when they enter the service or sign up to attend a group or event. Demographic data may also be collected alongside evaluative data to enhance understanding of the successes and development opportunities for the service. Service users should be encouraged to update the service when their data changes, and effort should be made to confirm accuracy of the demographic data held on a service user. There are some additional considerations to bear in mind when specifically collecting evaluative data. Evaluative data may be collected at point of intake and discharge, and periodically during the routine course of service delivery. See Part 3 of this guide for further information.

How should demographic data be collected?

1. *All monitoring data should be optional unless it is a requirement for accessing the service.*

Monitoring data is very useful and in some cases is a requirement of accessing a service. Where this is the case it should be clearly stated from the off-set. Otherwise, monitoring data should be optional. For most engagement, it is recommended that all questions are mandatory to answer, but that there is the option to select ‘prefer not to say’ so providing information is optional. For an open-text box, this can be done by providing written direction to type n/a, prefer not to say, information withheld, or similar if the service user does not wish to share the information.

If using multiple choice options for a demographic, the options should be laid out in alphabetical order, and these options should be consistent for each demographic across all services. Consideration should be given to how language changes over time are picked up and reflected in the options given in drop-down lists. For some multiple-choice questions, users should be allowed to select more than one option so that they can represent themselves more fully.

2. *Data for all services should be collected in a consistent manner.*

You should consider how to gather the information you require in the most efficient way from service users, ideally on a single intake form and record for each user, using a service-wide question bank as discussed in Section 3.1. This will make it easier to provide relevant and timely support with efficient referrals between staff teams. Only requiring a single point of data collection will additionally reduce barriers to your services compared with asking information multiple times.

3. *Data permissions and confidentiality must always be considered, and informed consent must be granted from the service user.*

A confidentiality and data permission agreement must be included and agreed to before the service user shares any personal information with your organisation. Providing context for information gathering at the start of the intake form may enhance response rate of optional questions because the service user will understand the reasoning for the questions. It is recommended that there is a brief version of the agreement included at the point of data collection, with signposting to your organisation’s full data permissions and privacy policy for further information.

The confidentiality and permissions agreement must clearly lay out:

- What the information shared will be used for
- What else may be done with the information
- How the information will be stored
- How long the information will be stored for
- Any anonymity surrounding data use

- When the organisation may be obligated to share service user information with other parties
- Brief outline of what the procedure will be if the organisation is obligated to share personal information with other parties
- How a service user may withdraw their personal information from the organisation

If using an online form, you should let the service user know what the next point of contact will be from your organisation and when they should expect it. You may also wish to separately ask the service user whether they consent to you contacting them for feedback.

4. ***Language surrounding many areas of demographics is ever evolving and changing, and language used within demographic data collection should be regularly reviewed against current best practice and the language used by service users.***

Language changes all the time and new ways of describing demographics will be developed. This can make comparing data over time difficult but can also be a positive thing for individuals articulating their identity and experience. Demographic data questions should be regularly monitored and developed with service users.

How should the data be maintained?

Store it: There are many ways to store data, from physical record keeping, to complete digital archiving methods. The technology and storage structures you choose to store your data will affect data design, security, ease of use, and methods of processing the data. Regardless of your storage means, user data should always be stored securely. Run regular checks on held data to pick up any problems or anomalies. Human error in data entry is unavoidable, so it is important to have processes in place to detect these and maintain data hygiene. This can often be done through use of tailored data requests or coded scripts.

If using a digital means of storage, all staff who work with the data must use secure passwords and two-factor authentication in order to access it. Data should not be housed across multiple platforms, wherever possible. In situations where this is unavoidable, processes (ideally automated) should be put in place to update data on downstream systems.

Keep it clean: Ensure confidence in data processing through normalisation and training, and have processes built in place (e.g. reminder texts) to ensure input has been completed.

Run regular checks on held data to pick up any problems or anomalies. Human error in data entry is unavoidable, so it is important to have processes in place to detect these and maintain data hygiene. This can often be done through use of tailored data requests or coded scripts that will generate a report of errors which can be manually reviewed.

***When the time comes, dispose of it appropriately*:** Have a data storage policy in place (this is what informs the permissions agreement with service users), and regularly appraise held data in accordance with this policy so it can be disposed of in the most appropriate means, which will depend on the data format.

2.2 Guidelines by Characteristic

Location

There are likely to be specific funding reasons for asking about service users' location. Often the first part of a service user's post code provides enough information to meet funding requirements and eliminates risks of incorrect data input by using place names. Postcodes also provide adequate data for geographical analysis of service provision if this is considered within evaluative criteria. It is recommended that location is gathered using an open text box:

> *"What is the first half of your* postcode*?*
>
> *Please enter* 'prefer not to say' *if you do not wish to respond"*

If further details of the service user's address are needed for a specific purpose they can be asked in a similar way.

If service users do not have stable housing or a permanent address, they can be encouraged to give an address of a trusted family member or friend with whom they might sometimes reside. Alternatively, they could provide an address where they receive their official correspondence. There should be accompanying guidance to inform the user what to do if they do not have stable housing or a permanent address.

Name

A service user identifier is important for updating a record and ensuring we can identify different service users. Usually, we use a name for this. Names should be collected for all service users where possible. It is recommended that this is done in two open response text boxes, one for first name(s) and one for last name. There should be accompanying guidance to inform the user whether they need to include their legal name, the name they are commonly known by, or the name they wish to be known by with the service.

Recommended language when asking an individual's name:

> *What is your name?*
>
> *Please fill this in with the name you would like for us to refer to you by. This does not need to be your legal name and you can change it at a later date if you would like*

This wording is informative and instructive and provides information about what is expected when answering the questions which reduces access barriers to the service. If the user's legal name or other names are required it is recommended that you add guiding notes to explain why. **Unless absolutely necessary, their legal name should not be requested as it is rarely required for service use. An exception to this may be to verify the identity of the user for the safety of other service users.**

In some circumstances it may be useful to ask the user if there are other names that they are known by. In this case the rationale for collecting this information must be included and the user must also be asked their preferred name, as above. Examples of this may be:

- If you need to know what name the service user is registered with at their GP
- If you need to know how to refer to the service user when communicating with family or friends
- If you need to communicate with another agency and you need to know the name the service user has registered with that agency.
- If the service user has previously registered with any of the services within your organisation using a different name.

Pronouns

It is recommended that a question on pronouns is included for all service users and that this is done using an open text box. However, some organisations may choose to use a drop-down list. If using a drop down list, users should be able to select multiple options and there should be space to write in other responses, as well as a 'prefer not to say' option:

> *What are your pronouns?*
>
> *Please share the pronouns you wish us to use for you. Please type 'prefer not to say' if you do not wish to respond.*

A drop down list requires your organisation to decide which pronouns to include in the list. It may be most practical to offer 'he/him' 'she/her' and 'they/them', as they are the most commonly used pronouns, and to provide a write in text box for other options:

> *What are your pronouns?*
>
> - *He/him*
> - *she/her*
> - *they/them*
> - *I would like to self-describe my pronouns [write in]*
> - *Prefer not to say*

However you may decide that this could feel exclusionary to people who use other pronouns and you may wish to offer other options. The risk in including a longer list is that you might miss one option or feel that you can never have a comprehensive list, and it is more inclusive of international communities and people using languages which aren't English.

The options you offer should be consistent across your organisation and ideally are chosen in consultation with service users, for example through a service user advisory or focus group.

Age

Age should be collected alongside guiding information about why it is required, for example for a specific age group-only service, safeguarding, monitoring and evaluation, or to contribute towards funding requirements. This will encourage people to respond if it is not a mandatory question. It is recommended that you ask for the service user's birth date so that their record can automatically update:

> *What is your date of birth?*
>
> *This information is required to ensure we can provide appropriate services to you.*

Date of birth

05/01/1999

Day, Month, Year

There are times at which you may wish to ask the service user's age rather than their birth date, for example:

- If you are conducting a 1-off interaction and the service user does not wish to tell you their birth date but you are required to gather age data for safeguarding, signposting or funding purposes
- In evaluation where you do not want the user to be identifiable

In this case, age should be collected in a single-select drop down menu, with a 'prefer not to say' option, or with an open text box:

> *What is your age? Please type 'prefer not to say' if you do not wish to respond.*

Gender, sexual orientation, and faith, religion or belief

The recommendations for collecting data on gender, sexual orientation and faith are broadly similar. For all, it is recommended that an open-text box is used with information to guide users on how to respond:

> *What is your gender? This does not need to be your 'legal gender', but who you are. E.g. non-binary woman, agender, man*
>
> *Please type 'prefer not to say' if you do not wish to respond*

> *What is your sexual orientation? E.g. gay, pansexual, heterosexual.*
>
> *Please type 'prefer not to say' if you do not wish to respond*

> *What is your faith or religion? E.g. Islam, Judaism, no religion.*

Please type 'prefer not to say' if you do not wish to respond

or:

A drop-down list or checkbox, allowing users to select multiple options, and providing an optional space for people to write in information about their gender, sexual orientation or faith:

'Which of the following best describes your [characteristic] (tick as many options as apply)?'

- *Option 1*
- *Option 2*
- *Option …..*
- *I would like to self-describe [write in]*
- *Prefer not to say*

When asking about gender, provide information such as "This does not need to be your 'legal gender', but who you are."

If using a multiple choice list, you may choose to offer a limited choice of options for these characteristics. You must carefully consider the options that you choose, as no list can be fully comprehensive. Using gender as an example, you could include the commonly used: Man, Woman, Non-binary, in another way [open text box] and prefer not to say.

You may choose to offer more options. The risk in including a longer list is that you might miss one option or feel that you can never have a comprehensive list. However, using a shorter list may also cause users to feel excluded.

Even within the authorship team of data-savvy trans people who have consulted different trans communities there are varied opinions on how to best word categories when collecting gender, and there is likely to be no 'perfect' way that everyone is happy with. It is important therefore to be transparent about the rationale behind the choices you are presenting and be clear on what you are asking of the respondent (i.e their gender not their trans status). This can be done by including guidance or an explainer as to why you have chosen to present certain options, e.g. that they have been selected for use based on community consultation/feedback, or that you must use them in order to meet reporting requirements for funders. Signposting to methods of providing feedback on this could also be useful in this instance.

It is important to carefully consider which question style and options work best for your organisation and regularly evaluate whether they are up-to-date and fit for purpose.

Trans status

It is recommended that trans status is collected in a separate question to gender, in a multi-select list with the option to respond 'yes', 'no', 'unsure', and 'prefer not to say', with the wording "Is your gender different to the sex you were registered at birth?":

Is your gender different to the sex you were registered at birth?

- *Yes*

- *No*
- *Unsure*
- *Prefer not to say*

The above wording is recommended over ''Do you consider yourself to be a trans person?" as not everyone in the above categories may identify with the word trans, and it is more inclusive of international communities and people using languages which aren't English to describe their gender. However, referencing sex registered at birth may be an issue to some service users who do not see their identity in relation to it, and there is once again no 'perfect' way to ask about trans status. Please consider which question style and options work best for your organisation and regularly evaluate whether they are up-to-date and fit for purpose.

Intersex/VSC status

Asking about intersex status, differences of sex development (DSD) or variations of sex characteristics (VSC) status is less commonly done than asking about some other demographics. Whilst there are different opinions from individuals within intersex and VSC communities about whether they identify with or find benefit from being part of LGBTIQ+ communities, there will certainly be LGBTQ+ intersex people or people with VSC accessing services, and there will also be intersex people or people with VSC who feel they would benefit from accessing them.

Having services fit for purpose for intersex people or people with VSC who do feel they would benefit from accessing them is as important as for people in other demographic groups. This may be particularly important when providing services related to reproduction, fertility, relationships, intimacy, and parenting. Collecting data on a person's intersex/DSD/VSC status ensures that they are able to have more relevant services and their needs and experience recognised. Further information can be found on the ICON UK website.

Additionally, commonly LGBTIQ+ services specifically include the 'I' and display the inclusive pride flag which includes the intersex pride flag. This makes it a matter of importance to consider service users intersex/DSD/VSC status during data collected with the intention of service delivery targeting and improvement.

As intersex/VSC status is something which is less commonly raised and recognised during demographic collection, it is recommended that you include an explainer of the subject within questions asked:

> *Some people are registered as male or female at birth, but are born with physical differences in sex anatomy, reproductive organs, chromosomes, and/or hormone function that do not fit the typical definition of male and female. These differences can be known as variations in sex characteristics, differences in sex development, intersex traits, or sometimes by specific medical terms (like Congenital Adrenal Hyperplasia or Androgen Insensitivity Syndrome).*

Were you born with any of these physical differences?

- *Yes*
- *No*

- *Unsure*
- *Prefer not to say*

Disability and Neurodiversity

It is recommended that disability and neurodiversity are asked about separately. This will allow space for both those who consider their neurodivergence to be part of their identity as a disabled person, and those who do not, to accurately represent themselves. When asking about disability, provide information that:

- Neurodiversity will be asked about separately
- Access requirements will be asked about separately

It may be beneficial to give a brief definition of the social model of disability with this question, which can be accessed on page 1 and 2 of this document.

When asking about disability, consider how detailed your questions are and the rationale behind them. Do you need to know about specific conditions or medications, for example?

A single-selection drop-down menu is recommended for these questions, with conditional write-in boxes to be used if the individual selects ‘yes’ or ‘unsure’:

Do you consider yourself to have any disabilities or long term health conditions?

- *Yes*
- *No*
- *Unsure*
- *Prefer not to say*

[conditional write-in box on selection of ‘yes’ and ‘unsure’]

Please add any further information you would like to share:

Do you consider yourself to be neurodivergent?

- *Yes*
- *No*
- *Unsure*
- *Prefer not to say*

[conditional write-in box on selection of ‘yes’ and ‘unsure’]

Please add any further information you would like to share:

Access Requirements

Asking access requirements allows you to support the service user to access the service fully and without discrimination. When asking about access requirements, it can be helpful to provide a few examples of what you are able to offer in a given context (provision at an in-person event will differ from a group video call, for example), to encourage responses. Providing illustrative examples can also be useful as a starting point to help service users consider what may be most helpful to them.

The ability to adapt service provision to service users' requirements will always have certain limits and it is important not to offer adaptations which cannot be fulfilled. It is better for a service user to know whether they will be able to access your service upfront rather than finding out further down the line once promised adaptations are not available. If you have dedicated resourcing for access requirements (such as a hardship fund that will cover certain types of costs like travel or childcare), consider explicitly stating that you have resources available to encourage access and participation and signposting where relevant.

An open text box, or single response drop-down menu is most appropriate for this question:

> *Do you have any access requirements to enable you to engage more fully with our services, or any medical conditions that we should be aware of to help keep you safe?*
>
> *(e.g. session plans, dietary requirements, additional languages, mobility or signing facilities, or closed captions in video calling. We may not be able to facilitate all but will discuss this with you.)*
>
> - *Yes*
> - *No*
> - *Unsure*
>
> *[conditional write in box on selection of 'yes' and 'unsure']*
>
> *Please specify:*

or

> *Do you have any access requirements to enable you to engage more fully with our services, or any medical conditions that we should be aware of?*
>
> *(e.g. session plans, dietary requirements, additional languages, mobility or signing facilities, or closed captions in video calling. We may not be able to facilitate all but will discuss this with you.)*
>
> *[open text box]*

Racialisation and/or ethnicity

It is recommended that an open-text box is used to collect information on ethnicity and racial background, with information to guide users on how to respond:

How would you describe your ethnicity or racial background?

Ethnicity and racial background relate to a sense of identity/belonging on the basis of race and/or culture, not necessarily your place of birth or citizenship.

[open text box]

However, multi-select lists are commonly used to align racial and ethnic groups to national surveys, funding bodies, and other institutions. It is important to balance rationale for the structuring of a question with acknowledgement of the flaws inherent in these categories. How exhaustive or inclusive the multi-select list needs to be will depend upon the user group and the aim of the data collection. It is important to ensure all who may be involved are able to represent themselves fully. It may assist service users' response to include the reason for the available options. If a multi-select list is used there should always be an additional short free-text box to allow for the respondent to describe themselves:

How would you best describe your ethnicity or racial background? (please select all that apply)

Choices for these questions are based on categories required by funding and Government bodies. These choices also allow us to compare our data with larger datasets. However, we understand there are deep flaws in this approach and that people do not fit easily into these boxes. If these boxes do not describe you, please use the free text response.

- *Arab or Arab British*
- *Asian or Asian British*
- *Black, Black British, Caribbean or African*
- *Mixed or multiple ethnic groups*
- *White*
- *In another way (please specify) [free text response]*

- *Prefer not to say*

As with other demographic questions discussed earlier, by creating a longer list you run the risk of exclusion but increase the ability for people to represent themselves accurately. A standard list of extended options used by many researchers in the UK is:

Arab

- *Arab or Arab British*
- *In another way (specify, if you wish).*

Asian

- *Bangladeshi or Bangladeshi British*
- *Chinese or Chinese British*

  - *Indian or Indian British*
  - *Pakistani or Pakistani British*
  - *In another way (specify, if you wish).*

Black

  - *African or African British*
  - *Caribbean or Caribbean British*
  - *In another way (specify, if you wish).*

Mixed or multiple ethnic groups

  - *White or White British and Asian or Asian British*
  - *White or White British and Black African or Black African British*
  - *White or White British and Black Caribbean or Black Caribbean British*
  - *Any other mixed or multiple ethnic backgrounds (specify, if you wish).*

White

  - *British, English, Scottish, Welsh or Northern Irish*
  - *Gypsy, Irish Traveller, Traveller or Roma*
  - *Irish*
  - *Polish*
  - *In another way (specify, if you wish).*

Prefer not to say

In another way (specify, if you wish)

It may be that conditional formatting is used to enable users to select more specific identities and groups within the broader initial category.

2.3 Other areas

It may be required for service provision to collect information on additional demographics. These may include:

- Employment status
- Housing status
- Carer status
- Parental status
- Experiences of migration
- Sex worker status

If demographics are collected as requirements for service provision they are commonly not able to be anonymised. It is necessary to inform service users whether their information will be anonymised or not to ensure they only share what they are comfortable with.

The recommended questions to use when asking about these items are similar to those in Section 2.2. Questions about these topics should be carefully considered and always developed in conjunction with service users of lived experience and other experts.

Part 3: Collection Guidelines for Evaluative Data

3.1 Effective evaluation

Well designed evaluative data collection aids in:

- Establishing whether an organisation or project has met its outcomes
- Determining what changes may be needed in a particular service area's implementation or delivery
- Planning future projects
- Measuring a service's impact on its service users
- Setting realistic expectations for service users
- Gaining funding for future projects and services

However, it is common for third sector organisations to struggle with obtaining sufficient feedback to comprehensively demonstrate the impact of the service. This may be due to:

- The breadth of services provided
- Lack of capacity within teams to collect and analyse the data
- Lack of familiarity or knowledge with data collection and analysis amongst the team
- Insufficient communication of the importance of data collection to the staff team
- Certain user groups being less confident or motivated to provide feedback

These issues can be mitigated to form a well managed mixed method evaluation approach which effectively provides the needed information.

1) *Ensure your methods are accessible and targeted to the service user group*

If the feedback method is suitable to the service user group you will increase response and engagement and reduce the time needed to collect the feedback. For example, a survey and case studies may be used for service-wide feedback, whereas for a specific youth group there may be regular interactive informal survey methods and 1-2-1 chats as part of ongoing activities and an annual focus group feedback session. Feedback for a counselling service may be very different to feedback for sexual health testing. It is key that all feedback pathways provide a mixture of a high volume of quantitative data supported by more in-depth qualitative data. This may require imaginative methods to be used and discussion with the service users to make sure the method is fit for purpose.

2) *Align feedback markers with project or organisational aims and outcomes*

If the requested feedback does not show how the organisation is meeting its strategic aims then much more work will need to be done to get the required level of understanding of user experience. Make sure that the organisational aims are reflected in the requested feedback.

3) *Measure the impact of the organisation on the service user*

This may sound obvious, but it is common for feedback to ask how the service users' lives have changed without reflecting on whether the organisation had any involvement in that, reducing the effectiveness of the feedback.

Instead of:

> *"How confident do you feel in your gender identity?"*
>
> *- 1 = low self-esteem, embarrassed or ashamed, I wish I wasn't trans…*
> *- 2*
> *- 3*
> *- 4*
> *- 5 = very proud of my gender identity, happy about who I am*

Consider:

> *"Has the organisation helped you to feel more confident in your gender identity?"*
>
> *-1 = the organisation has made a negative difference to my confidence in my gender identity*
> *- 2*
> *- 3 = the organisation has not made any difference to my confidence in my gender identity*
> *- 4*
> *- 5 = The organisation has made a positive difference to my confidence in my gender identity*

4) *Support less heard service user groups to contribute feedback*

Certain groups, such as young people, people of colour, and working class people, are less likely to provide feedback to services. This is for many reasons, a key one being that they have lower confidence that they will be listened to. Groups such as these can be supported to offer feedback by building trusted partnerships which ensures the service user knows they will have their opinions heard and acted upon. Consider:

- Specific focus group for marginalised service user groups
- Having any feedback groups led my someone with lived experience of the specific topic
- Transparent process of actions taken in response to service user feedback
- Creating a service user reference group who take a lead role in the evaluation and improvements of the organisation
- Providing alternative feedback options which are more accessible to the group

5) *Motivate service users to provide feedback*

Our experience tells us that service users who know why they are providing evaluative data are more likely to do so. Informing users what the impact of their contribution will be (for example supporting the organisation to access further funding to keep the service running, to be used to make improvements to the services) will aid in service user response. In addition, asking a service user for specific feedback for the team member that supported them has been found to increase response rate

6) *Have an organisational evaluation plan and a single streamlined collation of feedback data*

Organisations with multiple services commonly have multiple feedback pathways and store evaluative data in different ways. In addition, it is common for evaluation to be done on an ad-hoc basis without a systems-wide evaluation plan. This prevents an organisation-wide approach to service user understanding and service improvement. An organisational evaluation plan will be able to prevent later issues, such as over- and under-surveying of service users, gaps in required data, and capacity or skill gaps. This plan may answer questions like:

- How often will the data be collected?
    - Will it be done solely at point of intake and discharge, or on a regular basis throughout the service user's engagement with the service?
    - Will there be any follow-up with the service user? (Be sure to get consent!)
- What methods will be used to gather feedback?
- What type of resourcing is available to analyse the data? Some types of qualitative data can be more labour-intensive and time consuming to analyse, but can produce very rich findings.
- What will be done with the analysed information?

A centralised database or filing system will make it simpler to analyse the data and the organisation is more likely to effectively use the information.

3.2 Best practice ideas

1. *Include an explainer note*

A brief explainer note at the beginning of the form, interview, case study or focus group reiterates the purpose of collecting the data and can include a link to a more detailed privacy policy and contact information. If appropriate and relevant, it can be helpful to include an example here of how previous data collection has specifically improved services for the service's target population (demonstrating accountability). This is also the time to indicate whether the information the user discloses will be anonymous.

2. *Ask the user their reasons for accessing the service*

A service user’s needs and motivations for accessing a service can be initially assessed through the means of a multichoice list (either checkboxes or dropdown) with a free text box or conversation at a first or early point of interaction.

Inclusion of a list of what the service **can** provide (informed by the service’s intended outcomes) on intake forms acts as both an illustrative example for the service user and a source of measurable data for the service to compare against at point of discharge. The multichoice list also allows a service to set reasonable expectations for its service users in addition to gathering data to measure itself against.

Inclusion of a free text box along with the multichoice list not only allows the service user to relate any particular needs that aren’t addressed by the checklist but can also provide data to discern any emergent issues in the service user base.

If your organisation offers services for individuals in crisis, this can be a useful point to mention them.

3. *Measuring Feedback*

It is likely that any evaluative data collection exercise will contain a mix of closed and open ended questions dependent on the nature of the service, and so recommendations for specific questions will not be discussed here. However, general recommendations include:

- Include open-ended questions wherever possible and practical in evaluative forms, even if it is a catch-all “is there anything else you wish to tell us?” or a comment on the individual who interacted with the service user. This keeps the data collection instrument from feeling impersonal and transactional.
- Having a bank of questions or a template which all service areas draw from allows for consistency in collecting evaluative data.
- Use a service-wide system which can be edited or adapted to suit specific service outcomes, but code arising themes across all services.
- Consider using a visual analogue scale (VAS)[1] in place of a Likert scale for relevant closed questions asking service users to measure data which cannot directly be measured (pain, service user satisfaction etc). See accompanying slides for a working example.

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[1] https://en.wikipedia.org/wiki/Visual_analogue_scale

Conclusion

The effective collection, management and use of data can enhance community service provision and ease the process of demonstrating organisational impact. The recommendations included within this document are intended to support organisations to use best-practice processes when handling data.

Best practice data guidelines are ever-changing and this guideline captures a 2024 snapshot through the lens of supporting trans, non-binary and gender diverse people to be fully included within data collection and enabling services to most effectively meet their aims. The authors hope this document will be of use to relevant organisations, and welcome comments, suggestions and additions to the included material.

When transferring these recommendations to organisational practice it is likely that there are limitations in place which prevent idealised data management in all areas, and choices must be made based on practicality. Consideration should therefore be given to upholding ethical and accessible standards when using non-idealised data practices. Pushing back on limitations which uphold systems of oppression, and explaining the reasoning for data practices, are key methods to reduce systematic discrimination and organisational complicity in resultant hurt, and are the most important recommendations within this data collection and management guideline.