Person-centred intelligence: Implementing data collection

The Strategy Unit and Ipsos MORI

About this guide

- This guide forms part of the Strategy Unit and Ipsos MORI's series about person-centred intelligence
- It outlines the options for implementing measures of person-centred care. These include; adding new questions to existing data collection, undertaking new data collection either in-house or through a supplier.
- Having worked through this guide, readers should have an awareness of the options for implementing data collections and some of the wider considerations about doing so.

Contents

Adding to an existing data collection

Enhancing an existing data collection

One option to reduce the resources required is to use or enhance an **existing** data collection. If looking at existing work that may be useful, consider the following:

Confirm that the existing data collection meets requirements, by assessing it alongside the criteria described in our ‘selecting a methodology’ guide.

Check any additional questions against those already existing, to make sure that they do not duplicate or clash in some way, that they can be asked in a single data collection, and that the questionnaire is not then too long.

Additional questions should be added at the end (if existing data collection is tracking change over time) to ensure they do not affect responses to earlier questions. If additional questions are added earlier, treat questions after with caution, especially if there are logical reasons why they could be affected by earlier questions added in.

How changes will impact the supplier (if a supplier has been used). Discuss this with them and obtain a quote for any additional costs.

Ensure changes are communicated to necessary people, for example staff or patient representatives, this also includes if guidance/comms change.

Undertaking a new data collection

A new data collection

If undertaking an entirely new data collection, first work through the steps outlined in the guides on ‘designing and selecting a sample’ and ‘selecting a methodology’.

Then move onto implementing a new data collection, which will include decisions about;

- How frequently to collect the data
- Whether to implement the data collection in-house or use a supplier

Deciding the frequency of data collection

There are two broad options for the frequency of collecting data:

Option 1: Collect the data on a rolling basis as patients and carers use services and staff deliver them

This is necessary when data is collected at the service rather than afterwards. It can be more resource intensive, as work needs to be ongoing to encourage data collection. In addition, there will be some decisions to make around the points at which the data are analysed.

Option 2: Carry out data collection at a specified time as a single collection rather than on a rolling basis

If collecting data after a patient or carer has used a service, or if collecting data from staff, this is likely to be done best via a single, rather than rolling collection, as it will be less resource intensive (both from a time and cost point of view). However, there may be a trade-off with recall to be considered.

Further consideration: survey fatigue

Consider how many times participants are asked for feedback. Be aware of overlap with other surveys that may be running, such as the National Staff or Patient Survey Programmes.

Data collection in-house vs using a supplier

The following questions should be asked when deciding whether data collection should be implemented in-house or using a supplier:

Does the **capability** exist in-house? A supplier is needed if necessary technology (tablets or kiosks) is not available.

Does the **staff resource** exist in-house? For example, telephone interviewing is time intensive and might not be possible in-house. Equally, staff resource may not be available to coordinate mailings (for postal surveys) or programme an online survey, or to collate and process the data.

Does the **resource exist to pay** for outsourcing?

Can the organisation's **data protection and confidentiality procedures** be adhered to if conducted by a supplier, particularly if transferring patient or carer data?

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Undertaking a new data collection - implemented in-house

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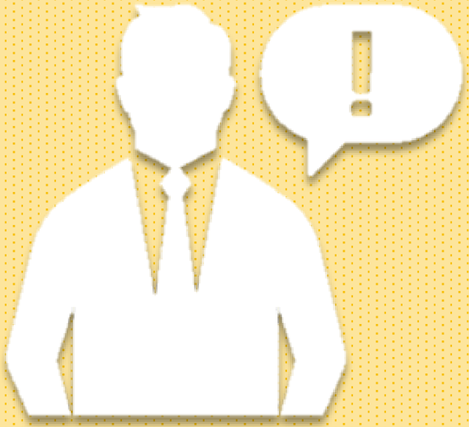

Please note!

The following section should be read if you are planning to implement a new data collection in-house. It provides some details about how to approach implementation, depending on the type of methodology.

You only need to read the information about the methodology you have selected (please click on the links below):

- Completion while still at the service, for patients and carers
- Completion via paper
- Completion via online survey

Completion while still at the service, for patients and carers (Part I)

If opting for this approach, frontline staff are likely to be central to ensuring participants are invited to take part and encouraging them to do so. The following steps are likely to be helpful:

Identify which staff will be asked to approach patients and carers: There needs to be clarity about whose responsibility it is to do this.

Make it as straightforward for staff as possible: It needs to take as little time as possible, and ideally be incorporated into current systems or processes so that they don’t forget.

Check technical aspects: If opting for tablets or kiosks, check that there is room in the right places for kiosks, that there are sufficient tablets, that Wi-Fi will work and so on.

Provide transparent objectives: Be clear with staff about the motives for the data collection and how it will be used, emphasising where relevant that it will not impact on patient care or on their practice. Also emphasise the benefits and justification for undertaking the data collection.

Completion while still at the service, for patients and carers (Part II)

Identify why staff would be motivated to help: This might involve highlighting to staff what they, or their patients, can gain from taking part in a data collection.

Appoint Champions or Implementation Leads: This is particularly useful where data collection is implemented across multiple sites or teams. It means that someone at each site or in each team is encouraging staff to approach patients or carers, is available to answer their questions, and can deal with logistics, such as making sure paper cards are returned to a central team.

Prepare staff in advance: Evidence suggests that training on how to recruit participants and deal with difficult scenarios aids smooth implementation, as does helping staff to familiarise themselves with the measures beforehand.

Provide clear and flexible guidelines: Guidelines on the data collection process need to include which participants are eligible to take part, the timing and frequency of when to ask and the location of administration. However, some studies have also identified that flexibility in the data collection process is necessary due to variability in the acuity of patients.

Completion while still at the service, for patients and carers (Part III)

Demonstrate management commitment: Professionals tend to be more willing to engage in the process of data collection when management show appreciation for the additional work involved and when management themselves become deeply involved in the process.

Data collection through collaboration: At times, the burden of data collection can fall on a small number of staff, so consider ways to get all staff engaged in the process to avoid this.

Monitor responses: The number of responses help to identify whether processes are working or if they need tweaking. This will also help in determining if there are certain staff/teams/departments that don’t seem to be working well and require more support. Also, look at the quality of data that is being produced, to see how the measures themselves are working.

Feedback the results: Close the feedback loop by communicating findings and impact to staff, (consider involving them in co-designing responses to data). Demonstrating the use of the data is a way of thanking staff for their efforts and see the outcomes – this is useful if this data collection is repeated in the future.

Completion via paper (Part I)

Paper completion may be via a questionnaire sent to a patient or carer's house, or a form completed while at the service. Practical tips include:

Do not include personal data on the paper form: If the names and addresses of participants are on the same form that they provide their answers, this is personally identifiable information. There are two options:

- Send it with a covering letter, so that any personal details are on the letter and not on the form. The two can be linked by printing a participant's unique reference number on both.
- Putting a name and address label on the envelope and not including any personal details on the form.

Include a unique reference number: This has the following benefits:

- Being able to link the responses to other administrative data held for the participant (for example, diagnosis).
- Being able to track responses so that reminders can be sent only to those who have not yet responded.
- Being able to remove someone's data from the collection if they make this request (in line with GDPR).

Completion via paper (Part II)

Make the layout as simple and attractive as possible: When participants look at the paper form, it should appear simple to complete, with very clear instructions, not cluttered and appealing, for example including some colour (although this will add to printing costs).

Include a reply-paid envelope if mailing out: This means participants do not need to pay anything to participate, and it encourages response. Second class postage is fine.

If completing at the service, provide a secure box for responses: This ensures that when participants put their responses into a box, others will not be able to look at them.

Completion via paper (Part III)

It is also important to consider the options for processing the returns. The choice depends on volumes of returns expected, the number of questions and internal capacity to process them.

If processing **internally:**

- **Develop a system and capture this in instructions,** so that multiple people can help and interpret the findings. You could mark up a questionnaire that can be used as a template.

- Enter them into software such as **Excel,** so the data can be manipulated.

- Consider **quality checking** a proportion of the data input, to check there are no issues.

There is an option to get the data **processed externally**, particularly if numbers are large.

Some organisations will manually enter data; others will have scanning technology useful for larger samples. If you are going to use a supplier for scanning, it is advisable that the supplier tests compatibility first.

Completion via online survey (Part I)

There are two broad options for an online survey using software like Survey Monkey:

1. An **open survey link**: This will not let you link back to a specific individual, so if you use this approach, make sure the online form gathers all the information you need (for example, condition, service and so on). However, a single link sent to everyone will be logistically easier to administer.

2. A **unique survey link**: This means each participant receives their own link and you can link their responses back to other data. As for the postal survey, linking back has the following benefits:
    - Being able to link the responses to other administrative data held for the participant (for example, diagnosis).
    - Being able to track responses, so that reminders can be sent only to those who have not yet responded.
    - Being able to remove someone's data from the collection if they make this request (in line with GDPR).

However, it may be difficult to administer, as each participant needs to be sent something different, requiring a mail-merge.

Completion via online survey (Part II)

Other considerations for an online survey include:

- As for a paper survey, it is important to make the layout as **simple and attractive** as possible, with it appearing simple to complete, with very clear instructions and not a lot of cluttering.
- When sending the invite out, you need to **be very careful not to copy everyone's email addresses into an email**, as this is a GDPR breach. Either do it through a mail-merge (ideally checked by a second person before sending) or ensure the BCC functionality is used.
- For staff, make efforts to enable them to **access their email at work**. Ideally staff will have a private place where they are able to complete a data collection.

Undertaking a new data collection – using a supplier

Please note!

Please read this section if you are planning to implement a new data collection using a supplier.

It provides some details about how to work with the supplier and respective roles.

Working with a supplier (Part I)

When selecting a supplier, procurement procedures should be followed. It is useful to obtain multiple quotes (around three) so that costs can be compared. The approaches of suppliers should also be compared. When providing a specification for suppliers to quote against, it is useful to give as much detail as possible.

If working with a supplier, the following are likely to be needed:

Agree the questions to be asked: Providing the supplier with a list of measures and questions that you wish to ask, or through a conversation with the supplier to discuss the different options and obtain their advice. You will need to agree the final question set (and layout, if relevant).

Confirm the methodology: This includes the sample design and actions to be taken to increase response rates.

Work through data protection and confidentiality implications: There are a number of areas to work through, covered later in this guide.

Working with a supplier (Part II)

Provide contact details (where required): Either provide the supplier with a complete list of potential participants and ask them to select the sample on your behalf, or select the sample yourself and provide this to the supplier.

Agree any covering letters, emails or leaflets also being provided: This ensures the data collection is being introduced to participants correctly.

Be available to respond to queries from participants: The supplier should be able to deal with most of the queries from participants, but there may be some that they escalate.

Publicise the data collection and encourage response: This depends on the approach selected and activity by which the organisation can encourage response. Please see the section on maximising response rates for more information.

Agree on data and reporting: Agree with the supplier how you want to receive the data, the format of any reports and structure these should have. You will also need to review and sign-off any reports.

Making data collection accessible

The importance of ensuring accessibility

There are multiple reasons to ensure a data collection is as accessible as possible:

To support **reliability of the data,** by a collection not systematically excluding some groups of people because they are not able to take part.

To **ensure those who want to can take part** in a data collection, for inclusivity purposes.

To comply with **Equality and Diversity requirements**.

To ensure accessibility, think through the needs of the target population. Provisions can then be selected based on this analysis of the specific cohort of participants being approached. The following slides provide ideas for specific populations.

Ensuring accessibility for those who do not speak English as a first language

Making provision for those who do not speak English as a first language:

- Providing **translations** in other languages (selected depending on the profile of those invited to take part). This is costly, but if data collection is targeted at a population speaking a specific language, there is value in this.
- Using a service such as **Language Line**. This works by conducting a three-way call with the interviewer, participant and Language Line, which is a pragmatic and less costly approach. Ideally, data collection materials would include information in different languages so participants are aware of this service (this could be adapted from major national surveys e.g. the GP Patient Survey).
- Encouraging participants to **get their friends and family to help them** to complete the data collections.
- Ensuring **staff have the information required**, and are sufficiently prepared, to help participants, possibly including **active support** to help them complete it.

Ensuring accessibility for those who are visually impaired

Making provision for those who are visually impaired:

- Making a paper questionnaire available in **large print or Braille**.
- Using **software** that allows participants to increase the font size on the screen.
- Encouraging participants **to get their friends and family to help them** complete the data collections.
- Ensuring **staff have the information required**, and are sufficiently prepared, to help participants with this, possibly including **active support** to help them complete this.
- Allowing **completion via the telephone** where required (i.e. the participant calling the contact details on the invitation and being talked through the questions).

Ensuring accessibility for those with learning disabilities or low literacy levels

Making provision for those with learning disabilities or low literacy levels:

- Providing **Easy Read** versions of the questionnaire.
- Including some images for guidance (for example, smiley faces or sad faces).
- Encouraging participants to **get their friends and family to help them** to complete data collections.
- Ensuring **staff have the information required**, and are sufficiently prepared, to help participants with this, possibly including **active support** to help them complete this.
- Allowing **completion via the telephone** where required (i.e. the participant calling the contact details on the invitation and being talked through the questions).

Other ethical considerations

Other considerations…

There are also a number of other ethical considerations, including:

- Ensuring that participants have **easy access to someone** if they have any concerns, e.g. providing contact details on invitations to participate.
- Marking correspondence as **‘Private and Confidential’** so that others don’t look at and find out about the participant’s health condition.
- **Ensure that it is appropriate to approach** all those in the sample, e.g. removing patients who have died, parents who have had miscarriages/stillbirths and so on.
- If children aged 15 and under are included, **parental consent** must be sought, and this could also be considered for 16 and 17 year olds.
- Trying to ensure **privacy**, e.g. if staff are completing a data collection or if a patient or carer is via a tablet or kiosk.
- There are also additional safeguards for **patients who are more vulnerable**:
    - Including **signposting people** to organisations if they require further support.
    - **Collecting the data in a different way**, e.g. using paper forms or individual staff following up on concerns.

Maximising response rates

Why response rates are important

If those who complete a data collection are different to those who do not complete a data collection, there will be **bias** in the sample. For example, if patients are surveyed online and there is a group of patients who experience worse outcomes who are also less likely to have access to the internet, then the results will not be representative.

A high response rate can therefore reduce the bias in a data collection. In practice, a high response rate is only one indicator of a data collection’s quality, because if those who complete it are similar to those who do not, then there is less bias for the survey.

Maximising response rates

Shorter questionnaires: The quicker a collection is to complete, the higher the response rate will be.

Simple questionnaires: If the questions are too difficult to answer, people will be put off. This means selecting measures that work for the audience.

Attractive design: In addition, the less onerous a questionnaire looks, the more likely people will be to complete it. This means aiming for a simple and clear layout.

Personalisation: Using names where possible to encourage people to take part.

Timing: For patients and carers, collecting data at a service will likely generate more responses than those collected after they have left the service. Similarly, staff are more likely to provide data where they have the time and equipment to do so as part of their roles.

Maximising accessibility: This helps ensure the data collection is inclusive.

Maximising response rates

Multiple and varied contact: Patients, carers and staff can be sent reminders to increase response rates. This is most successful where the reminders have different messages (for example, the wording of the invitation being adapted each time), and take a different form (like a letter and a postcard rather than two letters).

Multiple modes of completion available: To maximise opportunities to respond, for example paper and online, or paper and kiosk/tablet, or offering a telephone number if people are unable to complete it themselves.

Incorporating it into other processes: When relying on staff to collect data from a patient or carer, if doing so as part of a standard procedure they will be more likely to remember and collect the data (for example, if it is incorporated into standard information already collected). Similarly, when collecting data from staff if it can be incorporated into current collections (rather than a separate and additional collection) there will likely be more responses.

Maximising response rates

Targeting effort: In general, younger people and those living in more deprived areas tend to be less likely to respond to data collections. Where these factors are known to be linked to the item being measured, an option would be to target additional effort at achieving responses from these participants, to try and minimise non-response bias.

Confidentiality: Provide reassurances of confidentiality, so participants are comfortable responding.

Closing the feedback loop: In general, where participants have seen previous feedback being used to instigate change, they are more likely to respond in the future (particularly relevant for staff).

Publicity: General publicity about the data collection, for example via posters on wards or in clinics, or information on the intranet for staff, can raise awareness of the collection.

Ready to move on?

The operational aspects of data collection:

☑ When adding to an existing data collection, check it is fit for purpose, adding questions at the end and communicating change.

☑ When designing a new data collection, decide how frequently to collect the data, and whether to collect the data in-house or outsource it to a supplier.

☑ When implementing a new data collection in-house, consider practical steps for how to approach this whether collecting data at the service, by paper, or online.

☑ If implementing a new data collection via a supplier, the supplier will need input from you at key points.

☑ It is important to think about the target population and ensure that the data collection is accessible given the audience. This includes for those who speak English as a second language, people with a sensory impairment and people with learning disabilities or low literacy levels.

☑ There are further ethical considerations to work though, to make sure that participants are appropriately approached and supported.

☑ Ensure you understand the importance of and how to maximise response rates.