Dementia

Post Diagnostic Support

HEAT Target

Information Flow Mapping Guide

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DRAFT
Contents

1.0 Background ............................................................................................................................................. 3
2.0 Purpose of this Document .................................................................................................................... 3
3.0 What is Information Flow Mapping? .................................................................................................... 3
4.0 Why use Information Flow Mapping? .................................................................................................. 4
5.0 How to carry out Information Flow Mapping in your area ................................................................. 4
6.0 Reporting ................................................................................................................................................ 8
7.0 Engagement and Communication ......................................................................................................... 9
8.0 Further information ............................................................................................................................... 9
9.0 Appendices ............................................................................................................................................ 10
   9.1 Appendix 1 – Example of a Current State Detailed Information Flow Map ...................................... 10
   9.2 Appendix 2 – Draft High Level Ideal State Information Flow ........................................................... 11
1.0 Background

Improving post diagnostic support (PDS) is one of the two key improvement areas in Scotland’s National Dementia Strategy¹ (June 2010) and Standards of Care for Dementia in Scotland² - Action to support the change programme, Scotland’s National Dementia Strategy (June 2011)

In April 2012, the Scottish Government announced its intention to introduce a post-diagnostic support HEAT target to ensure people with dementia receive the help they need following diagnosis. This HEAT target will come into effect from April 2013.

The national PDS dataset will be available on the Information Services Division (ISD) website shortly.

2.0 Purpose of this Document

The purpose of this document is to provide guidance to NHS boards and their key partners on a technique called Information Flow Mapping, that can be used to ensure systems are in place to capture the key data points for the measurement of the target.

3.0 What is Information Flow Mapping?

Process mapping can be defined as a way of developing a 'map' of a process within a system. It will help you to map the whole patient journey or diagnostic pathway with a range of people who represent the different roles involved in managing and delivering care using that process. Process mapping can be used to help a team understand what happens, where the process and system problems are, identify areas for improvement and assist with the design of improved processes.

Information flow mapping is a subset of process mapping which aims to provide a pictorial representation of what data is collected along a process, and how information flows through a system.

4.0 Why use Information Flow Mapping?

Information flow mapping can be helpful in a number of ways. It can help to:

- **Document the current state** (what actually happens, not what we think happens). This includes identifying:
  - where data is currently captured (may be multiple points)
  - who is involved in collecting data
  - gaps in data collection
  - duplication of data input
  - any confusion around definitional issues for data points
  - inconsistency in how people interact with information systems along a pathway

- **Design a new process (ideal state)** that ensures
  - all the relevant data is captured
  - duplication of data entry is removed
  - unnecessary data collection is stopped
  - there is clarity on roles attached to collecting data
  - there are clear definitions for data points
  - systems are in place to extract and collate the relevant data

- **Inform the development of an action plan** that will ensure all the key information is being collected in the most efficient way possible.

5.0 How to carry out Information Flow Mapping in your area

Please note that this guidance presents it as a linear process moving smoothly from one step to the next. In reality, the process can be a lot more messy with you moving backwards and forwards between different steps as you develop a progressively better understanding of what is currently happening and what you actually want to happen. So don’t worry if it doesn’t all go so smoothly in practice, the key is that you understand what’s currently happening, you agree what you want to happen and then you develop a plan to move from where you are to where you want to be.

There are six key steps involved in information flow mapping:

**Step One - Obtain a process map of the current pathways to diagnosis and post diagnostic support (PDS)**

This means you need to be clear:

- **Which individuals/teams are currently involved/are you planning to involve in diagnosing dementia** (as you will need them to collect a variety of information around the referrals for diagnosis and the characteristics of individuals being diagnosed)
- **Which individuals/teams are currently involved/are you planning to involve in providing the PDS link worker role** (as you will need them to collect a variety of information around the actual provision of the PDS)
• What is the pathway from those diagnosing and those providing PDS (so you can check that all those who diagnose have a clear pathway for accessing PDS)
• Who the Link workers are (teams/ settings/ employers etc)

Starting with a map of the current pathways is useful for a number of reasons;

• It provides clarity around what happens with people interacting with the aspect of the care system being scrutinised, thereby immediately helping to identify areas for improvement.
• It can highlight any instability in the operational processes which need to be addressed. The clearer and more stable the underlying operational process, the easier it is to gather information from it in a systematic way.
• It serves to ensure that an information flow process is developed around an operational one and not vice versa – it is rarely appropriate to design operational processes around data requirements.
• It frames the information flow mapping work in the right context – the primary aim of service improvement work is to improve the quality of care we provide for individuals using our services. Information flow mapping should not be viewed as an end in itself, but rather it should serve to give us the information we need to make the necessary improvements to, and reporting on, the system of care. Establishing the operational process first helps to keep your stakeholders focused on why information flow mapping is important.

**Step Two – Understand what information is currently collected (current state)**

For those diagnosing dementia and providing the PDS link worker role establish:

• What information is currently collected?
• Which systems are they currently collected in? e.g. Paper Clinical Case note, PiMS, HELIX, TRAK etc
• Is the same information collected by more than one person or in more than one person (duplication)?
• What IT systems (if any) they use at present? Is it used across the whole NHS Board or are there gaps?

There are a number of ways to do this. One approach is outlined below;

• Identify who will undertake the initial scoping work, along with timescales.
• Use operational process map (see Step One) as basis of enquiry to begin with – but be open to flexibility as these may not be right.
• Secure some time with key team lead(s) to get a general idea about the steps of the information-flow and produce a high level information flow.
• Using the high level draft, seek more in-depth information around each step by talking to admin staff (exact processes, trigger that identifies when to record data, what is recorded, time involved in recording, where it gets recorded and the type of person recording eg clinician, admin etc)
• You now have enough information to produce a flow-chart of information recorded along the process. Formatting can be used to distinguish staff types, key transfer of care points, different information systems and so on.
Once this is developed, check it back with team leads to ensure it reflects the information they gave. NOTE the aim is not to seek consensus around each part of the system here. In fact, identifying differences in recording are very useful for the next steps. Where there are a range of differences in time, personnel involved, IT use and so on, these should be noted on the diagram. **The aim is to have a current state information flow diagram that can be used as a focus of discussion when the key stakeholders meet to establish next steps.**

The advantage of the above approach is that it yields good results for minimal investment in staff time. Further, it provides an objective and semi-validated information flow diagram prior to pulling the full stakeholder team together. The principle skills needed to undertake the work using this approach are:

- A good communicator (both verbal and written)
- A basic level of knowledge of the clinical/ operational pathway
- A basic level of knowledge of the information systems
- Able to use the main Microsoft office packages

An example of a current state information flow map is attached in appendix 1. This is not a Dementia example, however, it is a good illustration of an information flow map.

**Step Three - Develop an ideal state for your information flow**

Your ideal state should aim to provide information that will enable;

- You to measure whether you are delivering the target
- Useful information for the management of the target including information that will support clinicians and care workers to deliver PDS
- Recording of the above with the minimum of bureaucracy and administrative burden. The absolute ideal is an operational process for providing care, from which all of the required data can be gathered at no additional cost or time.

As a minimum, you need to identify what information is needed to measure the target. Appendix 2 provides a draft high level ideal state information flow map in relation to the PDS HEAT Target. National data points are identified in **blue** text and all others are potential local data points.

When developing your ideal state, consider other initiatives and interfaces that may exist around this area. It may be possible to incorporate changes into this process that deliver further organisational benefits, such as recording personal outcomes data.

**Step Four - Look at your current state and your ideal state and agree a plan for moving from one to the other**

One way of doing this is to gather the key stakeholders in one place. Key stakeholders are likely to include professions involved in diagnosing individuals with dementia, someone to represent each specialist Mental Health clinician group involved in delivering the post-diagnostic support link worker role, any voluntary sector staff involved in delivering PDS link worker role, administrative
staff, the relevant IT systems managers and trainers, and project support for this piece of work. It may also be appropriate to include the executive sponsor for the project depending on context.

Please note that you may find it more productive to separate out the primary care element of this work into a separate focused piece of work as there are likely to be considerably challenges attached to extracting the relevant data from the primary care systems (separate national guidance is being produced on this).

As a general rule, clinicians require at least six weeks notice in order to plan availability, so it’s important to identify a date as far in advance as possible. This can be done as step two above is commencing.

Prior to your meeting, the current state and high level ideal state information flow diagram should be circulated to all likely to attend. Develop an agenda for the meeting that explicitly states the objectives of the meeting, the pre-reading requirements and, if appropriate, indicative timings and leads for each part of the discussion.

Copies of the current state information flow and the high level ideal state information flow should be available on the day. There are various options for structuring the workshop but within it you need to cover:

- A discussion around your current state map so there is a common understanding of the issues or discrepancies. Those identified are likely to be (but not limited to!) a mixture of inconsistent use of IT, inconsistency at transition points in care, gaps and duplication in recording, lack of appropriate training in how to use the IT systems in question, and IT system restrictions.
- A discussion around the ideal state so you have an agreement on who should be collecting what data in which systems.
- What needs to be addressed to move from one to the other. You may find that a combination of responses is required including issues such as:
  - Do staff identified as link workers require IT training? Local agreements may be needed to allow access to IT systems e.g. 3rd sector staff accessing NHS IT systems.
  - What IT system(s) (if any) you want them to record the information for the target on e.g. should they use their existing system or do you intend to get them access to another system, or to use the excel data collection tool?
  - Do you need to make changes to IT system(s) e.g. the addition of new fields/ pick lists to ensure it is consistent with the data points?

There will likely be certain issues identified that either cannot be resolved or cannot be resolved without further work (such as changes that might require investment in IT). These should be recorded and parked for the project sponsor’s attention.
Step Five - Develop an action plan

An action plan should then be put in place that enables the work needed to get from current to ideal state to take place. The action plan should attach specific timescales and leads responsible for each task.

Step Six - Review and Amend

Evaluate the new processes as soon as possible and be open to changing if required. Ensure that you build in early milestones that allow you to test out how the new process is operating, and seek feedback from staff involved in gathering the data on how it’s working and how it could be improved further. Remember that a vital part of establishing robust data capture processes is ensuring that those inputting the data get useful information back. This guide does not cover what information you may want to report back – but you are unlikely to get good quality data if you are not summarising and feeding it back to front line services in a useful format.

And remember, this guidance presents it as a linear process moving smoothly from one step to the next. In reality, the process can be a lot more messy with you moving backwards and forwards between different steps as you develop a progressively better understanding of what is currently happening and what you actually want to happen. So don’t worry if it doesn’t all go so smoothly in practice – they key is that you understand what’s currently happening, you agree what you want to happen and then you develop a plan to move from where you are to where you want to be.

6.0 Reporting

Implementation of the HEAT target begins on 1 April 2013. You will need to put in place a robust reporting system to ensure that the required information for both local and national monitoring of the target can be obtained.

Some key questions to consider:

- What information do you require locally in addition to the national dataset to enable your local monitoring of the target?
- How will you ensure the information is as up to date as possible at the month end for collation and return at NHS Board level?
- If more than one system how are you going to collate this?
- How will you collate the data from different systems for each individual?
  - i.e. if diagnosis on one system but information about post diagnostic support offered is on another system
- How will it be collated within the timescales?
- Will you need to set up a partnership level reporting database in order to pull all the information together?
- What information do you need to have locally in order to manage this process e.g. who are the key people in each team you will liaise with for submissions etc.
The first national report to monitor progress towards the HEAT target will be expected from your NHS Board by end of May 2013. In cases where no data is available a nil submission should be submitted instead which contains qualitative information on progress towards implementation of the target.

### 7.0 Engagement and Communication

In order to successfully undertake work to implement measurement the aspects of the HEAT target engagement will be key. Good engagement will be needed to ensure that all everyone is aware of the target, of what their requirements are with regards to collection of data, and of where and who to go to if they have any questions e.g. it will be important to clarify the roles of individual staff with regards to data recording and ensure you have buy-in. Engagement is key to all aspects of target implementation e.g. it will be required with GP’s to ensure everyone newly diagnosed is identified so that services can put PDS in place. Further information on developing a communication and engagement strategy can be found [here](#).

### 8.0 Further information

If you require further information on the new Post Diagnostic Support Target the key contacts are:

| Target Scope/ Purpose and Wider Policy Context | David Berry  
Dementia Policy Lead  
Scottish Government  
Tel: 0131 244 3098  
Email: david.berry@scotland.gsi.gov.uk |
|-----------------------------------------------|-------------------------------------------------|
| The Dataset, Measurement and Submission of Data to ISD | ISD Scotland  
Email: NSS.ISDDementiaPDS@nhs.net |
9.0 Appendices

9.1 Appendix 1 – Example of a Current State Detailed Information Flow Map

Referrals – Pre-allocation

- Secretary records all referrals and date of referral in local database, Medical Records record this on PMS.

Allocation (every week)

- Matrix alignment, therapy alignment and therapist alignment are considered and decided upon.

Referrals – Post-allocation (2-3 days after allocation)

- Outcome of allocation meeting is inputted in local database for allocated referrals and in PMS for ‘inappropriate’ referrals by secretary. Patient notes are made up for all by secretary.

- Level 2
- Level 3
- Level 4

Opt-in (2-3 days after allocation)

- Secretary records date of the letter sent in local database, sends copy of letter to GP and puts one copy in patient file.

Appointment letter (2 days after opt-in)

- Secretary sends out appointment letter, sends one copy to GP and puts copy of it in patient file.

First appointment / Assessment

- Secretary records date of first assessment in local database, Clinician records contact in diary, PMS and patient file. (All recording done within 7 weeks)

- Group
  - Clinician records attendance on PMS and local database. Clients may go on wait list, depending on start date of group

- Level 2 – Short-term intervention
  - Clients are usually seen straight away and do not often go on waiting list

- Level 3 and 4 – Long-term intervention
  - Clients go straight on waiting list. The Secretary records this on the local database (within 2-3 days after assessment)

DHA / CHA

- Clinician records this in diary, on PMS and patient file (within 1 week)

Follow-up appointment

- Clinician records this in diary, on PMS and patient file (recorded within 1 week)

DHA / CHA

- Clinician records this in diary, on PMS and patient file (within 1 week)

Discharge

- Clinician discharges client from PMS and calls discharge letter to GP. Copy of discharge letter in patient file. Secretary records discharge info in local database (recorded within 1 week)

- Date of discharge should be the date of the discharge letter

Outcome measures

- Clinician collects data on assessment and last contact and records on information sheet. Secretary records this in local database at discharge
9.2 Appendix 2 – Draft High Level Ideal State Information Flow

High Level - Ideal State - Information Flow Map

Data Points:
- CHI
- Gender
- Age band
- Care Home resident flag
- Date referred for Dementia diagnosis
- Date referral received for Dementia diagnosis

Data Points - Data Points are in BLUE - all other data points are potential local data points

Data Points:
- Date Dementia diagnosis confirmed
- Sub type of Dementia
- Stage of Illness at diagnosis
- Residence of patient at diagnosis

Data Points:
- Date PDS offered
- Date allocated to link worker

Data Points:
- Date PDS starts / 1st contact with link worker
- Outcome of initial offer

Data Points:
- One month date past
- Status of PDS 1 month after start
- Six month date past
- Status of PDS 6 month after start

Data Points:
- Twelve month date past
- Plan in place at 12 months
- Status of PDS 12 months after start (pillars 1, 2, 3, 4 and 5)
- Date of end of PDS
- End of PDS reason

Data Points - Questions to consider:
Are the data points currently available and if not, how easy would they be to collect?
Which systems are they currently collected in?
If one data point is captured on different systems (i.e., diagnosis) how will you get the most comprehensive data set?
How will you collate the data from different systems for each individual?
- i.e., if diagnosis is on one system but information about post-diagnostic support offered is on another system
Are there any issues around data accuracy that need to be addressed?
Where will you pick up diagnosis from and can you accurately pick up the date of diagnosis?