



The Scottish Smoking Cessation Minimum Dataset

BACKGROUND, RATIONALE AND FAQs

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INTRODUCTION

At the time of this document's publication in March 2010, specialist smoking cessation services in Scotland have been recording their practice through the Minimum Dataset (MDS)¹ and Information Service Division (ISD)² Scotland's electronic smoking cessation database for over four years, with the fourth annual report of service performance due in May 2010. During this time the quality of recording by services has improved dramatically, the MDS itself has gone through a detailed review process by a multi-disciplinary review group³ and performance targets for national health outcomes are now based on the information captured by the database.

The shift from many local systems towards one standardised national system for data recording in smoking cessation, as would be expected, has not been without its difficulties. While an extensive mapping exercise carried out by a PATH Information and Evaluation Working Group⁴ recognised the necessity of standardising the way smoking cessation services in Scotland capture data, the mapping and consultation process undertaken uncovered some of the difficulties in designing a set of questions that would be appropriate for services across the country.

Stopping smoking is a complex human intervention, and as such, it is recognised that while the numbers generated by the minimum dataset and national electronic smoking cessation database give some insight into how our National Health Service assists smokers who want to quit to do so, it does not tell the complete story. Because of this, it should always be made clear that the statistical output of the MDS and database describes one part, not the entirety, of the work carried out by smoking cessation services in Scotland. Services can and do spend time and resources assisting smokers who may not currently be ready to quit, and who fall outside of the criteria for inclusion into the database, but who nevertheless may achieve positive outcomes (like significantly cutting down consumption, or moving them closer towards being able to quit).

Our understanding of how best to describe and capture these other indicators of success is limited, but developing, and will perhaps one day form part of a more comprehensive, holistic, picture of smoking cessation services. At present however, with pressures in the form of hard outcome targets for smoking cessation at the national level,⁵ the logistical challenges for services following the introduction of the national pharmacy scheme, and the everyday difficulties of helping individuals stop the use of an addictive product that is the largest cause of premature death and disability in Britain,⁶ efforts must continue to improve the quality of the data and adherence to the guidelines for use of the minimum dataset and cessation database.

This document is intended to provide MDS and database users with an understanding of the background, rationale and development of the dataset and answers to common questions about the interpretation of the dataset items and use of the database.

1. BACKGROUND

1.1 PATH

Partnership Action on Tobacco and Health (PATH) was established in 2002 to support the implementation of policies outlined in the UK Government's 1998 White Paper *Smoking Kills*,⁷ and in subsequent policy documents, including Scotland's 1999 White Paper *Towards a Healthier Scotland*.⁸ PATH is a joint initiative between ASH Scotland, NHS Health Scotland and the Scottish Government to reduce the prevalence of tobacco use in Scotland. Funded by the Scottish Government and managed by ASH Scotland, PATH works with key partners to develop and roll out best practice in the areas of training, data collection, evaluation and cessation.

1.2 Data collection mapping study

In 2002 PATH conducted a mapping study to find out more about the data collection, monitoring and evaluation procedures of smoking cessation services in Scotland.⁹ Smoking cessation professionals from across the country participated in a detailed interviews and provided copies of their data collection forms. The results showed immense variation in the way services operate, including great diversity in the sorts of information that services gathered about their clients and how this information was used.

This diversity meant that it was difficult to interpret and compare outcome data on service provision and to measure if cessation targets were being met. PATH was tasked with making recommendations to enhance the validity and consistency of data collected by smoking cessation services, both for the purposes of national monitoring and for reporting to local stakeholders and policy makers.

1.3 Report of recommendations

In August 2003 PATH produced a Report of Recommendations relating to data collection, monitoring and evaluation for smoking cessation services in Scotland.¹⁰ Smoking cessation practitioners, research experts and other relevant professionals were involved in extensive consultation during the production of this report. A major feature of this report was a (draft) *minimum dataset* – the essential information on clients to be gathered by smoking cessation services. The Report of Recommendations also included a (draft) protocol for using the minimum dataset – a set of guidelines offering standard definitions of key terms and standard procedures for measuring cessation outcomes.

The minimum dataset was devised with involvement from smoking cessation professionals and research experts, with decisions based on existing good practice and evidence from secondary sources. It also aimed to allow comparison with smoking cessation services elsewhere in the UK. Where possible the minimum dataset aimed to take into account the information that services were already collecting.

1.4 Piloting the minimum dataset

In December 2003 PATH set up a piloting study to find out more about the practicalities of using the minimum dataset, from the perspective of smoking cessation professionals. A variety of smoking cessation services throughout Scotland took part in the piloting, to ensure that the questions and options in the dataset were easy to understand, answer and administer. It was important to test how the minimum dataset worked, to get feedback on it and make any necessary revisions before finalising a version for use across Scotland. The piloting phase ran till the end of May 2004. This allowed services enough time to test the questions on a number of clients and also carry out 3-month follow-ups where practicable.

In June 2004 PATH convened a meeting of its Research and Evaluation Working Group to discuss the draft minimum dataset pilot study. Members of the working group include smoking cessation professionals (including some who took part in the piloting), experts in the field of academic tobacco research and staff from PATH and ASH Scotland. The group went through the dataset question-by-question and discussed feedback from the piloting and their thoughts in relation to each item. Possible modifications to the draft dataset were discussed and a number of changes approved.

1.5 The first minimum dataset

The first 'finalised' version of the dataset was incorporated into ISD Scotland's National Smoking Cessation database, a web-accessible data entry system with reporting and analysis features. The system was piloted in 2005 with the first year of complete national recording being the 2006 calendar year. From 2006, annual reports using the information gathered through the minimum dataset and national database have been published, and are available from: www.scotpho.org.uk/home/Publications/scotphoreports/pub_scotphoreports.asp [Accessed 1 March 2010].

1.6 The MDS review

Following the first year of successful recording, the National Cessation Database Project Board (the group responsible for oversight of the database), who at the time were receiving a large number of request from services to examine more in-depth technical or content issues regarding the dataset, commissioned an Expert Review Group (ERG) – a mix of service representatives, statistical and research advisors, and representatives from other stakeholder organisations - to undertake a review to ensure that the MDS:

- *reflects service developments across Scotland*
- *permits monitoring and evaluation at both a local and national level*
- *shows meaningful comparisons between Health Boards across Scotland*
- *supports local service delivery*
- *documentation reflects any changes made and enhances understanding of the rationale behind the dataset.*

The group reviewed the MDS closely from 2007 - 2008, in consultation with the NHS Board smoking cessation co-ordinators, and produced a report of recommendations in June 2008.¹¹ The electronic database was revised to reflect these recommendations, with the changes coming into effect in January 2009.

The most recent version of the dataset (including a version for use in the Community Pharmacy Smoking Cessation Service), guidelines for use, and supporting documents are available on the ASH Scotland website: www.ashscotland.org.uk/ash/4240.html [Accessed 1 March 2010].

2. RATIONALE

Given in this section are some of the reasons, from the report of recommendations¹² and elsewhere, as to why a system like the minimum dataset and smoking cessation database is necessary and useful.

2.1 Monitoring, evaluation and audit

Monitoring (reviewing the progress of work by routinely collecting information), evaluation (assessing your work and its outcomes, based on evidence from recording activities) and audit (comparing practice with set and agreed standards) are crucial parts of the work of smoking cessation services, as they are any other evidence-based practice. It is necessary to monitor what we are doing in order to make sure we are doing it well, and that we have the information to demonstrate that we are making continuous improvement. The minimum dataset aids services and national monitoring bodies to collect information that will enable them:

- *to see what they have achieved*
- *to improve their performance*
- *to identify what activities are most and least worthwhile*
- *to learn from experience*
- *to contribute to the evidence base for good practice.*

2.2 Local usage

The minimum dataset and accompanying database provides a useful tool to collect important baseline information on clients accessing services and outcomes of interventions. The reporting functions of the database provide essential statistical information for both local use and national monitoring. The information in the dataset can help smoking cessation specialists to determine which kinds of people are most likely to quit using the service and what approaches are most successful.

In turn this knowledge should assist in tailoring services so that a greater number of people can be successfully helped to stop smoking. The minimum dataset will elicit information that services can use to demonstrate that services are effective in treating smokers. This can be used to encourage funding and resources for the sustainability and enhancement of services and to show that services make a difference.

The electronic database allows a wide range of items to be collected for local use, in addition to the mandatory MDS items. From spring 2010 onwards, a new 'local use' facility will be put in place, allowing local services to gather custom, locally-defined, data. For more information on this facility contact ISD's database manager Adrian Hyndman (adrian.hyndman@nhs.net).

2.3 Targets

The minimum dataset and cessation database is currently used to measure NHS Board's progress toward the relevant *HEAT*¹³ (Health Improvement, Efficiency, Access, Treatment) target: *'through smoking cessation services, support 8% of your Board's smoking population in successfully quitting (at one month post quit) over the period 2008/9 - 2010/11.'*

ISD issues boards with periodic updates detailing their progress towards the *HEAT* targets, boards also have access to the database's reporting features to examine in detail their own local service performance data.

As the MDS and database are the only system through which data on smoking cessation at a national level is currently available, it is likely it will be a key reporting tool in future targets beyond 2011.

2.4 Clinical guidance

Nationally-issued guidance on service operation stresses the importance of monitoring and data analysis for smoking cessation services. The *National Institute for Health and Clinical Excellence* guidance on smoking cessation services¹⁴ recommends that services should 'set realistic performance targets for both the number of people using the service and the proportion who successfully quit smoking' and that they should '[a]udit performance data routinely and independently and make the results publicly available. Audits should also be carried out on exceptional results – 4 week quit rates lower than 35% or above 70% - to determine the reasons for unusual performance, and to help identify best practice and ensure it is being followed.'

Although NICE guidance technically has no authority in Scotland, it is interpreted into Scottish-specific guidance ('*Scottish perspectives on NICE guidance*', prepared by NHS Health Scotland) which normally does not deviate significantly from the original. The forthcoming *Guide to Smoking Cessation in Scotland 2010*¹⁵ will include a similar recommendation for data auditing in Scotland, though without threshold values for 'unusual performance' as per NICE above. Nevertheless, investigating data outliers of high or low quit rates is something which individual services may want to consider.

2.5 Freedom of information

Since *The Freedom of Information (Scotland) Act (2002)* was put in place in 2005, public authorities have been obliged to make available information about how their organisation is run, if requested. The sort of information that can be requested is wide ranging and could include anything else that helps the public make better informed decisions and choices about the services they use (e.g. quit rates, specific documents related to smoking cessation and other related information). It helps, therefore, to have good quality data to hand in case appropriate requests for information are made. PATH has prepared best practice guidance on how MDS users should gather and use client data.¹⁶

3. FREQUENTLY ASKED QUESTIONS

Q

A

1. Who do I get in touch with if my question isn't answered here or on the MDS page at the ASH website?

If your question is to do with the database itself (that is, the web-based interface that is used to record data) then your question should probably go to ISD's database manager Adrian Hyndman (adrian.hyndman@nhs.net). If your query is to do with one of the 31 items on the MDS, the guidance supporting the MDS, or you have a query about the meaning or interpretation of a particular item, get in touch with the PATH team at ASH Scotland (enquiries@ashscotland.org.uk) and they will direct you to the most suitable person to answer your query.

2. What does 'minimum dataset' mean exactly? What about 'mandatory' and 'additional' data?

The term 'minimum dataset' refers to a core set of essential information to be collected about each client setting a quit date through smoking cessation services, at present consisting of 31 items. This data is anonymous, and does not contain information that could be used to accurately identify clients. Mandatory data is the same thing – the basic data that all services are required to collect.

As the name suggests, additional data is any other information that services might want to collect above and beyond the mandatory minimum dataset. The database itself contains many items beyond the mandatory MDS ones, each service should explore the additional data they can collect and decide what to record locally that makes sense for them

3. Why is a minimum dataset necessary?

The minimum dataset, electronic database and accompanying guidelines allow services to gather uniform standardised data. Similar minimum datasets are already used in other parts of the UK where reliable statistics are available on smoking cessation service outcomes. Agreeing on particular criteria (for example, the criteria for quitting) between and across services is challenging, but it is necessary in order to provide meaningful results that can be compared across regions and with other nations.

4. Do we have to use the same form that is available on the ASH Scotland website? It is rather cramped and doesn't include the additional information that we would like.

No, in fact the form that is available on the ASH Scotland website is not really intended to be used 'as is'. It merely gives the items that should be included in the development of local forms (which are expected to be larger, as most services like to capture at least some additional data) - it is intended to be used for information and as an example.

Most services have their own client registration forms and we recommend that these be adapted to ensure that the information required by the minimum dataset is included. If they wish, services can use the PATH form as a template, to which they can add any information they want to collect locally. Services may wish to collect the baseline and follow-up information on different forms – it really depends on what your local needs and circumstances are.

5. Our service collects some information that is not in the minimum dataset. What should we do?

PATH's Report of Recommendations encouraged services to collect any information in addition to the minimum dataset that they think is important. At the very least your service should be collecting all the minimum dataset information, which is required for national monitoring purposes. By all means you should also continue to collect any other information for your own monitoring and evaluation purposes. You should adapt your own data collection forms to ensure that both the minimum dataset and any other information are incorporated.

6. Do these data collection and follow-up procedures not expect rather a lot from services?

The information collected is extremely useful for monitoring service provision. While there is a wealth of published evidence on cessation more generally, the MDS and database offers an opportunity to make a unique, Scottish, contribution to the evidence base. The information can be used to show that stop smoking services are helping to address inequalities in health (as a recent study of the 2007 Scottish data demonstrated¹⁷) and to help to secure funding. We appreciate that few treatment services gather such a level of data on clients and service outcomes and it is of great credit to smoking cessation services that they collect this information.

7. How are we meant to implement the minimum dataset and follow-up, especially coordinating with the pharmacists in our area?

We appreciate concerns over finances and resources. We believe that the work of cessation services must be properly and realistically funded and that our recommendations can only work in this context. It is widely acknowledged that the Community Pharmacy smoking cessation scheme threw up particular challenges in data collection, adding paperwork and an extra logistical burden.

However, despite the many problems in their introduction and initial implementation, these systems are here to stay, and have largely been adapted to well by services. Although there is certainly an extra burden of work, the data gained is worth the effort, and the extra reach of a stop-smoking service through pharmacies that may be to some clients' preferences is advantageous. We recognise that all of this work must be sufficiently resourced in order to be effective however.

8. Will the minimum dataset tell us everything we need to know?

While the minimum dataset will provide a great deal of useful baseline and outcome data about clients using smoking cessation services, it does not tell us everything. It is therefore important that services continue to collect any additional information that they think is important. Additional research, at both national and local level, will also help to determine the attributes of the most successful approaches to service delivery.

9. Does every service/health board use the MDS and national database?

Information Services Division (ISD) Scotland have developed a web-based data management system/database for smoking cessation services in use throughout nearly every health board in Scotland since 2006. The system incorporates all the items in the minimum dataset, additional data items to meet local information needs and features for statistical reporting and generation of follow-up letters. The system is under continuous review under the oversight of a project board that meets regularly.

Generally, most health boards are now using the National Minimum Dataset. However, those who have invested considerable resources in local systems have retained these and make arrangements to allow transfer of data

from local systems to ISD for incorporation in national analysis. However, the data that is gathered is the same in the end.

10. I heard that it's possible to predict one-year outcomes from analysing 1-month data. Why then are we being asked to do a 12-month follow-up?

It is true to say that some research shows that longer-term cessation rates can, to a degree, be predicted from shorter-term measures. There are clear time and resource implications to longer-term follow-up, this (combined with the discouragingly high rates of clients who are 'lost to follow-up' and the focus of national targets on one-month success) leads some to conclude that effort put into following up at any period beyond one-month is largely wasted.

However, many researchers are keen to continue with the attempt to follow-up at longer periods because: a) there has never been a systematic review of Scottish stop-smoking service provision and it may be possible long term success here differs from other areas researched; b) it allows the continual monitoring of long term success to see how changes in service provision or other tobacco control measures affect it; and c) long-term success is important to measure because it is the thing that really matters for the intervention, and the client.

Hence it is PATH's recommendation that 3-month and 12-month follow-ups will remain for the time being, but the situation will be kept under continual review and be monitored by the National Cessation Database Project Board.

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