

The Minimum Dataset for Scottish Smoking Cessation Services (Including Pharmacies Offering the National Community Pharmacy Smoking Cessation Service)

Guidelines for Using the MDS

November 2017

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PATH is a joint initiative between ASH Scotland, NHS Health Scotland and the Scottish Government to reduce the prevalence of tobacco use in Scotland. Action on Smoking & Health (Scotland) (ASH Scotland) is a registered Scottish charity (SC 010412) and a company limited by guarantee (Scottish company no 141711).

PATH, April 2016

Notes on the most recent Guidelines update

This document is intended to support Scottish NHS Health Board Smoking Cessation Services (SCS) and pharmacies offering the national community pharmacy smoking cessation scheme in understanding and utilising the national Minimum Dataset (*MDS*).

What the Minimum Dataset is for

The MDS contains information that **must be gathered for clients who access and set a quit date with Scottish SCS and pharmacies** (that offer support in line with the national community pharmacy smoking cessation scheme). All clients who set a quit date and take part in a smoking cessation **intervention (in line with the definition of intensive/specialist services) should have their data recorded** - this is required for anonymous national reporting of cessation data.

It is acknowledged that this covers only one part of services' work, and services frequently act in other ways to support smokers who may fall outside the criteria for inclusion into the MDS (e.g. relapse prevention). The MDS is only for recording the outcome of specialist/intensive smoking cessation services through SCS and those services provided by pharmacies as part of the national community pharmacy smoking cessation scheme. The definition of these services is available from: www.healthscotland.com/documents/4661.aspx

Most recent updates (November 2017)

The changes to this document in comparison to the previous version are as follows:

• Addition of 5 items on 'referral source' - this is done following the proposal Smoking Cessation Coordinators Network to include 'Mental Health, Scottish Fire and Rescue Service, Social Care, Voluntary Sector and Workplace' as selection options.

If you have any queries regarding the MDS that are not answered by this document please get in touch with ASH Scotland at the address below.

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The Minimum Dataset for Scottish Smoking Cessation Services *April 2016*

For Office Use Only							
1. Client ID:							
2. Health Board area:				3. Clinic area/ty	oe:		
Client Information							
4. Date of birth:// 5. Gender: □ Male □ F						ale, pregnant? N □ Unknown	
7. What is the client's ethnic group? (Choose one section from A to F, then tick one box which best describes the client's ethnic group or background):							
A. White Constant Scottish Con	<i>groups</i> □ Any	ed or multiple ethnic mixed or multiple groups, please	As So Inc Ba Ba C So So	Asian, Asian Sco sian British Pakistani, Pakista cottish or Pakistan Indian, Indian Sco dian British Bangladeshi, angladeshi Scottis angladeshi British Chinese, Chinese cottish or Chinese Other Asian, Asia cottish or Asian Br ease specify	ani i British ottish or h or British an	D. African	
E. Caribbean or Black	□ Ar Arab	er ethnic group ab, Arab Scottish or British ther, please specify		Not Disclosed			
8. Employment status (ple In paid employment Homemaker/full-time Retired Not known/missing Other (please specif	e parent c	pr carer E	∃ Un∉	I-time student employed manently sick or o	disabled		

9. Full postcode:							
Tobacco Use and Quit Attempts							
10. On average, how many cigarettes does the client usually smoke per day?	11. How soon after waking does the client usually smoke their first cigarette?	12. How many times has the client tried to quit smoking in the past year?					
□ 10 or less □ 11-20 □ 21-30 □ More than 30 □ Unknown	 □ Within 5 minutes □ 6-30 minutes □ 31-60 minutes □ After 60 minutes □ Unknown 	 No quit attempts Once 2 or 3 times 4 or more times Unknown 					
	Intervention Details						
13. Referral source							
Community Dentist GP HealthPoint Health visitor Hospital Incentive Scheme Mental Health Midwife Pharmacist Practice Nurse Prison Scottish Fire & Rescue Service Self-Referral Smokeline Social Care Stop smoking roadshow Voluntary Sector Workplace Other (please specify) Health Health							
14. Date referred to service:	15. Quit date:	16. Date of initial appointment:					
17. Does the client consent to follow-up?							
□ Yes □ No							
18. Pharmaceutical usage							
 NRT only (one product at any one time) Varenicline only NRT and Varenicline (change in product) NRT and Varenicline (change in product) NRT and Bupropion (change in product) NRT and Bupropion (change in product) 							
Total number of weeks of known product use							
19. Intervention(s) used in this quit attempt							
 One to one sessions Group support (closed groups) Telephone support Group support (open/rolling groups) Couple/family based support Other (please specify) Unknown 							
20. Intervention setting(s)							
 Primary Care Pharmacy Educational establishment Other (please specify) 	 ☐ Hospital - Outpatient ☐ Workplace ☐ Home 						

21. Shared care between pharmacy and non-pharmacy services?					
□ Yes					
1-Month Follow-Up					
22. Was the client successfully contacted for 1-month follow-up?					
□ Yes □ No (Client lost to follow up) □ No (Client did not consent to follow up) □ No (Client died) □ Unknown					
23. Date follow-up carried out:					
//					
24. Client withdrawn from service at time of follow-up?					
□ Yes					
25. Has the client smoked at all (even a puff) in the last 2 weeks?					
□ Yes □ No □ Unknown					
26. CO reading confirms quit?					
□ Yes □ No □ CO reading not taken					
3-Month Follow-Up					
27. Was the client successfully contacted for 3-month follow-up?					
□ Yes □ No (Client lost to follow-up) □ No (Client did not consent to follow-up) □ No (Client died) □ Unknown					
28. Date follow-up carried out:					
29. Has the client smoked at all since the 1-month follow-up?					
 No Yes, between 1 and 5 cigarettes in total Yes, more than 5 cigarettes Unknown 					
12-Month Follow-Up					
30. Was the client successfully contacted for 12-month follow-up?					
□ Yes □ No (Client lost to follow-up) □ No (Client did not consent to follow-up) □ No (Client died)					
31. Date follow-up carried out:					
//					
32. Has the client smoked at all since the 1-month follow-up?					
□ No □ Yes, between 1 and 5 cigarettes in total □ Yes, more than 5 cigarettes □ Unknown					

Guidelines for Using the Minimum Dataset - *Overview*

The Minimum Dataset (*MDS*) consists of the core information that is to be collected for each client *who sets a quit date with a specialist smoking cessation service or pharmacy offering support in accordance with the national community pharmacy smoking cessation scheme¹, for the purposes of local and national monitoring and evaluation of smoking cessation services. It is important that all smoking cessation services and pharmacies use standard definitions of key terms and procedures to ensure consistency and validity of data collected.*

Full, accurate, and timely completion of the minimum dataset is crucial in order to obtain valid data and allow future follow-ups to be undertaken. Those involved in the monitoring and evaluation of services should read and understand the following guidance before using the minimum dataset and NHS Information Services Division's (ISD) electronic smoking cessation database.

Data Collection Forms

SCS in Scotland have developed in divergent ways to best meet the needs of their local population. This divergence manifests itself in the various ways services collect MDS information and at various stages of contact.

Services should ensure that whatever their local processes of data collection on smoking cessation, they should gather information on **all** the items detailed in the MDS. The MDS, as given in this document, may be used as a template form itself, or it may be adapted into existing local forms. NHS Board Smoking Cessation Co-ordinators should be consulted for details as to the recommended local practice.

Of course, services can (as many do) collect additional information above and beyond that included in the MDS.

Data Protection and Confidentiality

It is vital that all data is gathered and used in accordance with data protection and patient confidentiality guidelines. Clients should be given clear information on why information is being collected and what it may be used for. They should be informed that anonymised data will be used for monitoring purposes and asked for their consent to be contacted at a later date in connection with their smoking (i.e. at the 1-, 3- and 12-month follow-ups). Should a client refuse follow-up at any stage, records should be clearly noted to this effect. Clients have the right to refuse and this should not affect their right to receive treatment. If you intend to share client data with anyone, then the client's permission should be obtained beforehand. Data should only be used for the purposes for which permission was given.

For more information on issues surrounding data protection and client confidentiality refer to PATH's guidance on *Using Client Data: Data Protection, Client Confidentiality and Access to Information,* available online at: www.ashscotland.org.uk/ash/4241.html

¹ The definition of what specialist/intensive smoking cessation support should offer is available from: <u>www.healthscotland.com/documents/4661.aspx</u>

Guidance for Items 1-3: Client/Clinic Identity

1. Client ID

A system for allocating clients with unique identifying codes is required as a way of linking anonymised data and to enable resolution of any queries arising after submission of anonymised data. Services should devise their own system for allocating local identifying codes, avoiding duplication and ensuring consistency locally.

Please note that the national smoking cessation database also automatically generates a unique system ID/record number for each quit attempt record entered.

2. Health Board area

This question is asked so that service uptake across Scotland can be monitored at regional level. There are 14 options, reflecting each possible Health Board area:

- Ayrshire & Arran
- Borders
- Dumfries & Galloway
- Fife
- Forth Valley
- Grampian
- Greater Glasgow & Clyde
- Highland
- Lanarkshire
- Lothian
- Orkney
- Shetland
- Tayside
- Western Isles

Please note that the information regarding a service's NHS Board area is automatically generated by ISD's electronic national smoking cessation database system (based on the NHS Board area of the system user) and does not have to be entered manually.

Note: The State Hospital, Carstairs, has a separate code in line with its special NHS Board area status.

3. Clinic area/type

Services should record the clinic area or type. This field is locally defined and could be geographical clinic areas or clinic types depending on a particular service or reporting needs. Your local service manager/smoking cessation coordinator at NHS Board level will have defined the options in this field after liaising with NHS Information Services Division (ISD) Scotland's database manager.

Guidance for Items 4-9: Client Information

4. Date of birth

A client's date of birth is a key piece of demographic data, which is routinely collected in clinical settings. This item is required to measure uptake by different age groups.

5. Gender

This item is collected to measure uptake of services by men and women. Two options, male and female, are offered in the MDS. While it is recognised that there may be clients who have changed their gender from their sex at birth, for the purposes of this dataset self-reported and self-described 'current gender' is adequate.

6. If female, pregnant?

Services should ask **all** female clients if they are known to be pregnant. This is to measure uptake by pregnant women – an identified priority group for smoking cessation.

7. What is the client's ethnic group?

This question is included in the MDS to find out about uptake and cessation by individuals from different ethnic groups.

The categories to be used for ethnicity in the MDS are the same as those used for the recent 2011 Scottish National Census².

As with any system of categorising a fluid and culturally variable concept such as ethnicity, these categories may not be entirely unproblematic; however, this is the preferred structure for collecting ethnicity data in Scotland at the present time.

Clients should be asked to '... choose **one** section from A to F, then tick **one** box which **best describes** your ethnic group or background'. If they select any of the 'other' options they should specify what they designate as their ethnic group or background in the space provided.

Clients may want to go between choices or may need help to find the appropriate category (though the options have been designed to minimise this as much as possible).

If the client is uncomfortable about answering this question the 'not disclosed' option may be used.

² Further information on the 2011 Scottish Census is available on the census homepage: <u>www.gro-scotland.gov.uk/census/censushm2011/index.html</u>

8. Employment status

Employment status is asked in the MDS as a measure of socio-economic status in order to determine uptake of services by people of varying backgrounds.

This question is also useful at service level because it gives information that is potentially useful in relation to the context of an individual's tobacco use and quit attempt – for example, in their ability to attend a service, or possible levels of stress or isolation.

Clients should be asked to select one of the following options:

In paid employment	Full-time student
Homemaker/full-time parent or carer	Unemployed
Retired	Permanently sick or disabled
Other (please specify)	Not known/missing

For clients who are self-employed, the 'In paid employment' option should be selected. It is recognised that there are limitations with the use of employment status as a proxy for socio-economic status. For example, it does not distinguish between short and long-term unemployment and does not give an indication of income.

It is possible that some clients may not fit neatly into one category (e.g. persons who have taken early retirement, but continue to work part-time). In these circumstances they should be encouraged to select one option that they feel best fits their situation. If neither option fits then 'other' can be selected and details given in the space provided.

9. Full postcode

Full postcode (e.g. *EH2 2HB, IV1 1TR*) is recorded as a proxy measurement for socio-economic status. This is important for analysing the uptake of services and cessation outcomes for those who live in more disadvantaged areas. Although recognising its limitations (e.g. people from a 'disadvantaged' area may not themselves be 'disadvantaged' and vice-versa) it is the best available tool.

Postcodes can be mapped onto local information to provide a deprivation category score. Until relatively recently, in Scotland the standard deprivation measure – The Carstairs Index of Deprivation - was based on postcode *sector* (e.g. EH2 2, IV1 1), so it was not necessary to use the full postcode. However, since the 2001 Census there is a move towards a new measure, the Scottish Index of Multiple Deprivation (SIMD), which is an electoral ward based measure and **requires full postcode**.

The SIMD is based on 37 indicators across 7 domains: current income, employment, health, education, skills and training, housing, geographic access and crime. For more information on the SIMD, see the following website: http://www.scotland.gov.uk/Topics/Statistics/SIMD/

Although full postcode is an item on the dataset that could potentially identify a client (particularly in more rural areas), users of the national smoking cessation database should be aware that postcode is converted to 'data zone' area in the dataset that

NHS ISD Scotland has access to for central monitoring purposes which minimises/excludes such possible identification.

Guidance for Items 10-12: Tobacco Use and Quit Attempts

The following three items are asked in order to provide a measure of tobacco dependence and motivation to quit. At service level these are useful to help services provide appropriate treatment. They are also useful from a monitoring and evaluation point of view, to find out about uptake of services and effectiveness of different interventions in relation to clients' nicotine dependence. There is no perfect system for calculating dependence; the following three items simply offer a short and standardised way of measuring dependence across Scotland.

Note that responses to items 10 & 11 can be combined to give a score on the Heavy Smoking Index³, a measure of nicotine dependence.

10. On average, how many cigarettes does the client usually smoke per day?

This question is asked to a gauge client's intensity of tobacco use, and to provide further context to the quit attempt and outcomes.

Clients may provide an answer which does not neatly fit within these categories (e.g. 'usually I smoke 20 a day, but sometimes it's more if I'm stressed' or 'I smoke more at the weekends than I do during the week') and may ask for clarification as to how to answer this question. In this situation it should be emphasised that you are looking for the *average* number of cigarettes smoked per day and clients should be encouraged to select the option that best fits with their tobacco use.

If a client has recently stopped smoking prior to attending the service, please record here the average number of cigarettes they were smoking before they stopped.

For clients who use a form of tobacco other than cigarettes, many services use a 'tobacco conversion chart' to convert the amount of hand-rolled tobacco or pipe tobacco smoked into an equivalent value in cigarettes. The national smoking cessation database also contains a conversion formula that can be referred to when entering MDS data onto the system.

11. How soon after waking does the client usually smoke their first cigarette?

The question 'How soon after waking does the client usually smoke their first cigarette?' is used in combination with the items immediately above and below to gauge client's level of dependence on cigarettes, and to provide context to the quit attempt and outcomes.

³ Heatherton, T, Kozlowski, L et al. (1989) Measuring the heaviness of smoking: using self-reported time to first cigarette of the day and number of cigarettes per day. *British Journal of Addiction*, 84, 791-800.

Clients may initially offer a response that does not neatly fit within these categories (e.g. 'sometimes I smoke straight away, but sometimes I don't smoke for hours'). In these circumstances clients should be encouraged to select the option that best fits with what happens on most days.

12. How many times has the client tried to quit smoking in the past year?

The question 'How many times has the client tried to quit smoking in the past year?' is asked to measure the number of recent unsuccessful quit attempts and to provide further context to the current quit attempt and outcomes.

This question is, by nature, subjective and there are many possible interpretations as to what constitutes a 'quit attempt' (for example, some people might claim that they try to stop smoking every Monday morning, others may wonder if it means trying to quit using support from the smoking cessation service).

Clients may ask for clarification as to what exactly is meant by this question or what period of time without smoking qualifies as a quit attempt. If a client asks for guidance, encourage them to think back to how many times they have *seriously* tried to stop smoking (e.g. have managed to stop smoking for more than 24 hours) and to pick the option that best fits with their situation.

Guidance for Items 13-21: Intervention Details

13. Referral source

Following the Chief Medical Officer's chief executive letter CEL 01 - <u>http://www.sehd.scot.nhs.uk/mels/CEL2012_01.pdf</u> - on health promoting health services, NHS ISD Scotland is required to record data on additional performance measures, including the quit success following a referral from a hospital setting. In order to gather this data, standardised recording of referral source is required. This item includes hospital-based referral sources, and also a range of other potential healthcare and community sources.

14. Date referred to service

Items 14, 15, and 16 all track key dates for clients entering and using the service. *Date referred to service* should be completed to reflect either the date a client's details are referred to the smoking cessation service from an external source (e.g. from a GP or secondary care), or, if a client is effectively self-referring (they attend the service directly without having to see another healthcare practitioner), the date that they first attend the service (this may be the same as item 16 - Date of initial appointment).

This item, in combination with 15 and 16 will allow more detailed local and national analysis of a client's path through services, how long clients may take to set a quit date from their initial contact and give some indication as to waiting and referral times when the client is referred to the service from external sources.

15. Quit date

The QUIT DATE may not be the 'actual' quit date of a client, but the 'proposed or planned' quit date which clients aim to achieve. All clients, and only clients, who actually set a 'proposed or planned' quit date, will be included in the MDS for national monitoring and annual statistical reports.

It is recognised that this is only one part of the work smoking cessation services carry out. Many services expend resources and expertise supporting those who never set a quit date or those who have already quit and supporting them to stay quit. This is recognised in the way the national reporting is presented. However, for the purposes of outcomes measurement, the criteria must be something that is measurable, and standardised.

As services have evolved, it is recognised that a small proportion of clients may set a quit date between initiation of contact with the service (such as after an initial phone call with the service, or following contact with a referring health professional in a hospital setting) but prior to their first actual attendance/appointment. In such instances where a genuine quit attempt has begun shortly before first attendance the quit date may be recorded as the same date as the first date of attendance with the service (item 16). A client's quit date cannot be recorded as being before their first point of contact. To be eligible for recording in the MDS the smoking cessation support provided to such clients must still meet the definition of a specialist smoking cessation intervention in duration and intensity of support⁴. Alternatively if in discussion with the client, the quit attempt prior to first attendance was deemed 'halfhearted', the adviser may wish to suggest to the client that they set a new proposed or planned quit date which they can make a concerted attempt to prepare for.

The quit date gives a definite point from which to measure follow-ups, in particular for the purposes of monitoring against national and local targets. It also indicates that a client is serious about trying to give up smoking. Measuring follow-ups from the time of the quit date provides a standardised method that can easily be adapted by most services. The quit date model fits with guidance for the use of Nicotine Replacement Therapy, Bupropion and Varenicline, and with the practices of many smoking cessation services in Scotland. It also brings Scotland in line with the rest of the UK.

Clients who access smoking cessation services but do not go on to set a quit date or recent quitters seeking support to remain quit are, at present, beyond the scope of national monitoring. Nonetheless, it is appreciated that significant effort, time and resources are spent on clients who do not set a quit date. Services are strongly encouraged to collect additional information on such clients for the purposes of local monitoring, evaluation and service planning.

Staff should explain to clients the concept of a 'quit date'. They should also judge when is the right time to get a client to set a quit date. At initial contact with a service, for example, may be too early for this.

⁴ The definition of what specialist/intensive smoking cessation support should offer is available from: <u>www.healthscotland.com/documents/4661.aspx</u>

On the national smoking cessation database, once a client has had their 1-month follow-up data entered it is not possible to then go back and amend their quit date. If a client sets a new quit date, then this should be recorded as a new quit attempt.

16. Date of initial appointment

This should be entered as the date of the client's first actual session in the course of cessation support that they are engaging in (not the first time they make contact with the service, e.g. to enquire about the service provided or attend an open/introductory session to find out about the service and what it entails). When the support is provided remotely by telephone as a substitute for face-to-face support (for example, in rural and remote areas due to geographical constraints) then the first substantive session of telephone support should be recorded here.

Gathering data on this will, in combination with information on quit date and referral date, provide more detailed information on the various pathways and timescales as a client goes through the service. Local and national analysis of time from referral to first appointment will also be possible.

17. Does the client consent to follow-up?

This item is to verify consent to follow-up in the MDS. Consultation and discussion with services gives the impression that consent to follow up is generally high, and it is recognised that most services already use a locally devised template to ensure that clients consent to the follow-up procedure entailed by the MDS.

For the few cases where follow-up by the services is considered to be unwanted or intrusive however, it is important to incorporate this item as a 'final check' to record that consent has been sought. This is particularly important in the case of some services where the follow-up is carried out by a different organisation - or in a different location - to the one that carries out the intervention (which is not uncommon across Scotland).

If a client states they do not wish to be followed-up, then their views should be noted and respected.

18. Pharmaceutical usage

This item is included to get an indication of what form of Nicotine Replacement Therapy, Bupropion, or Varenicline was used - if any at all - and the length of time that these pharmaceutical products were used for.

The options provided allow services to specify if only one form of NRT was used at any one time (for example, staying on NRT patches for the entire course of treatment, or starting on patch but then ceasing patch use and changing to NRT gum), NRT combination therapy (for example, using patch and inhalator at the same time) and whether the client started on one type of product, then moved to another (for example, starting on Varenicline, then switching to NRT). The MDS collects information on pharmaceutical treatment (smoking cessation pharmacotherapies) used in the *current* quit attempt only and does not ask about anything used in the past.

In the field that asks for total number of weeks used, this should be a numeric value rounded to the nearest whole number. If the product use is discontinued (for example, due to adverse effects) the length of time used should still be recorded to the nearest whole number of weeks (which could be zero if, for example, the product is used only for one to three days before use is discontinued).

If, in the course of the client's quit attempt, there is a change in pharmaceutical usage, this information should be updated (note: for users of the national smoking cessation database, please update details on the 'current service use' screen). Note that, because at the one month follow-up the total duration of pharmaceutical (pharmacotherapy) use may not be known (that is, the client may still be on a course of treatment) - *this question should be revisited at the 3-month follow-up to ensure its accurate completion (with both product(s) used and 'weeks used' updated on the 'current service use' screen of the national smoking cessation database, as necessary).* If there is uncertainty over the total number of weeks used due to the client not being able to be contacted at 3 months to update the data entered at 1, or for any other reason, then the total number of weeks the product was *known* to be used should be entered.

19. Intervention(s) used in this quit attempt

The MDS gathers information on intervention types in order to see the range of approaches used and to compare outcomes. As the question phrasing implies, all approaches that were used by the client during this quit attempt should be selected.

The MDS collects information on interventions used in the *current* quit attempt only and does not ask about interventions used in the past. The MDS does not collect further details about the length, frequency or duration of sessions. As always, services may wish to ask for this sort of information in addition to the minimum dataset.

The options given are a result of the combination between standardised, evidencebased interventions (such as one-to-one sessions) which will be familiar to most, and additional items that are included in order to accurately categorise what is going on in Scotland's diverse services and capture developments. Below are items that may benefit from further explanation.

 Group support (open/rolling groups): This option is included to reflect development in services who offer this option to clients instead of, or in addition to, fixed membership or 'closed' groups. Inclusion in the MDS does not mean that the intervention type is 'endorsed' by PATH or the Scottish Smoking Cessation Guidelines⁵; to ascertain this, services should consult the relevant documentation. Inclusion into the MDS is at the request of services in order to

⁵ The smoking cessation guidelines for Scotland (2010) are available from: <u>http://www.healthscotland.com/documents/4661.aspx</u>

record their interventions accurately.

- *Telephone support:* This is used in some parts of Scotland, particularly rural areas, for clients who are unable to get to a clinic. Advice and support is given over the phone, rather than face-to-face.
- Couple or family based support: This is a popular approach in some areas, where clients receive support in pairs or in small groups, along with partners or other family members. This kind of approach does not fit in neatly with either one to one or group work and should not be counted as such.

Any type of intervention that does not clearly fall into any of the categories presented in the MDS should be recorded in the 'other' category, and described appropriately.

20. Intervention setting(s)

The MDS includes this item in order to gather standardised information on the location of the intervention – where it is delivered. It is recognised that some services already gather this type of data under *item 3 – clinic area/type*, however, this is not standardised, as different areas have arranged to use this field in different ways. This item offers some standardisation so, for example, we can see how many interventions took place in a pharmacy setting across the country as a whole.

Services should record here the setting(s) in which a *substantial part of the intervention is delivered through or takes place within.* If the intervention is split between two settings (for example, the client receives initial sessions of a one to one intervention in a secondary care setting, but is then referred to a primary care setting) then both should be recorded in the MDS. The options that are listed under this item on the MDS are below.

- *Primary Care:* This option should be selected if a substantial part of the intervention is delivered through any of NHS Scotland's Primary Care services (*excluding Pharmacies, see below*); for example GPs, Dentists, NHS walk-in centres and other non-hospital venues.
- Hospital Inpatient: Should be selected when the intervention is provided in an NHS secondary care setting, where the client has been admitted to the hospital as an inpatient and is resident at the hospital overnight, or for an indeterminate period of time.
- Hospital Outpatient: Should be selected when the intervention is provided in an NHS secondary care setting, and the client is not admitted to the hospital, or hospitalised overnight, but instead visits a secondary care site for treatment or diagnosis.
- *Pharmacy:* Any clients who receive a substantial part of their intervention through a pharmacy should be recorded here.
- *Prison:* Any specialist smoking cessation intervention that takes place within the Scottish Prison Service should be recorded as such here.

- *Workplace:* Where the intervention takes place as part of a structured, workplace-based programme of intervention.
- *Educational Establishment:* Where the intervention is set in any primary, secondary or tertiary-level educational establishment.
- *Non-NHS Community Venue:* This option is to record any interventions that take place in what might be described as a 'community venue.' This would include leisure centres, community centres, town halls, and similar.
- *Home:* This should be selected when one of the main settings for the intervention is in a privately owned home or residence.
- Other (please specify): Any setting which is not covered by the options above should be recorded here.

21. Shared care between pharmacy and non-pharmacy services?

Since the roll-out of the Public Health Service (PHS) contract amongst Community Pharmacies in Scotland during 2008, increasingly interventions may be split between specialist cessation services and pharmacies. This can be a positive feature in providing accessible cessation services that are responsive to client needs regarding time and place of delivery. The MDS gathers standardised information on what setting the cessation intervention is delivered under *item 20 - intervention setting(s)*. It is recognised that the cessation intervention may be split across multiple settings.

It is important that services **record all specialist smoking cessation interventions that meet the criteria set out in this document, and that each quit attempt is recorded only once, even if it is effectively 'shared' between different agencies**. For example: this includes cases where a quit attempt begins with a specialist service based in secondary care and the individual subsequently goes on to seek behavioural support for the same quit attempt with a local pharmacy. It would also include quit attempts that begin with a community pharmacy PHS smoking cessation intervention and go on to be supported by individual or group specialist smoking cessation service during the course of the same quit attempt. Shared care also includes interventions where support provided involves pharmacy and non-pharmacy services at the same time in addition to the above examples where the intervention is provided by one organisation, followed by the other.

This box should be checked if the quit attempt is shared in this manner between pharmacy and non-pharmacy services. To qualify as an agency providing shared care for a quit attempt, the service must provide a substantial part of the cessation intervention in the on-going quit attempt. This should include part of the structured programme of behavioural support the client receives as part of the overall quit attempt, and should be more than dispensing of pharmacotherapies.

Guidance for Items 22-26: 1,3, and 12-Month Follow-Up

Notes on Outcome Data

The most obvious outcome measure for smoking cessation services is quit rates/quit numbers. However, there are conflicting opinions amongst both researchers and practitioners of the best ways to measure and verify a quit.

While it is acknowledged that different criteria and guidelines exist, it is extremely important for data gathered through the MDS to follow as consistent a standard as possible in order to make comparisons within and between services nationally. Currently, we share the international standard (The Russell Standard)⁶ which England also operate to, and while there are certainly times where this model will be felt to be a less-than-perfect fit for every client that attends a service, it is still the most consistent and stable model available.

The minimum dataset records information on both short-term and longer-term quits. Clients setting a quit date should be followed-up at three points: 1 month, 3 months and 12 months post quit date.

Self-reported quits are used at all follow-up points, with additional carbon monoxide (CO) monitor validation requested at the 1-month follow-up point. A flow chart summarising the follow-up process is attached on pages 26-27.

1-Month Follow-Up

The 1-month follow-up is the core measure of short-term cessation success in the MDS.

Who to include in the 1-month follow-up

Services should attempt to follow-up all clients setting a quit date.

When to conduct the 1-month follow-up

The 1-month follow-up should be carried out immediately upon, or very shortly after, the 1 month date (exactly one month after the quit date). The first time at which a client should be contacted is 1-month after their quit date.

If they cannot be contacted at this time, further attempts (3 attempts are recommended) should be made within the subsequent 2 weeks of their follow up date. **Therefore, follow-ups should be completed within 6 weeks of the original quit date** (the one-month follow-up plus the two week window).

⁶ West, R., et al. (2005) Outcome criteria in smoking cessation trials: proposal for the common standard. *Addiction*, 100, 299-303.

If it has not been possible to contact a client within this time, the individual should be counted as '*lost to follow-up*'. Services are encouraged to make note of when follow-ups are due when the quit date is set; the national smoking cessation database can assist in planning this by notifying services when follow-up is due.

This cut-off point helps to promote meaningful and consistent data, and puts Scotland in line with procedures in England and international standards.

How to conduct the 1-month follow-up

It is preferable for the professional who provided the intervention to see the client *in person* for the 1-month follow-up. The smoking cessation adviser and client will have established a relationship in the preceding weeks which should encourage honesty from the client regarding their quit attempt. Seeing the client in person also fits in with the duration of intensive/specialist service and pharmacy smoking cessation programmes, where the client will still be in contact with the service at the time of 1-month follow-up.

Additionally, seeing the client in person enables a carbon monoxide monitor reading to be taken to validate the self-reported smoking status (see overleaf). If, in exceptional circumstances, clients cannot be seen in person, they should be contacted by another means (e.g. telephone or post) for follow-up.

22. Was the client successfully contacted for 1-month follow-up?

The first item in relation to the 1-month follow up is if the client was able to be contacted for the 1-month follow-up or not. The options presented and how to proceed depending on response given are below.

Yes Please now complete questions 23-26

No (Client lost to follow-up) No (Client did not consent to follow-up) No (Client died) Unknown Please now complete question 24

If the client *was* successfully contacted for follow-up then the date when follow-up took place should be noted in the following question. This is necessary to check what time period has elapsed since the quit date and follow-up, and to check it falls within the 6 week time period since the initial quit date was set. If a client has been contacted for follow-up, then the remaining 1-month follow-up questions (23 - 26) should then be completed.

If the client was *not* contacted for follow-up, then the reason should be noted by ticking the appropriate box - either because they were lost to follow-up, or because

follow-up was not carried out for another reason (the client did not consent to followup or the client has died).

If the client has not been able to be contacted for follow-up then **only question 24** (*client withdrawn from service at time of follow-up*) needs to be completed. Those completing the MDS information for clients do not need to record any other information and this should ensure that time is not spent completing questions which are not relevant.

The 3-month and 12-month follow-ups need not be collected if the client is lost to follow-up at the 1-month stage.

23. Date follow-up carried out?

The above question should be completed for all clients who were successfully followed up at the 1-month stage. This question allows services to check whether the follow up was carried out within the valid timescales set to ensure consistency across services within Scotland.

24. Client withdrawn from service at time of follow-up?

This item should be completed for **all clients** who set a quit date (even those who have not been able to be contacted for 1-month follow-up). The box is to be checked only if it is known that the client has *withdrawn from/is no longer in* the service at time of 1-month follow-up.

Being 'withdrawn from service' means that the client has started an intervention and set a quit date, but has subsequently dropped out of the service at or before the 1-month follow-up (i.e. they have stopped attending sessions and receiving support for whatever reason). Clients who fall into this category should still have follow-up attempted, and the follow-up outcome noted, but their effective 'withdrawal from service' should also be noted by checking this box.

If the client is still in service/still receiving support at the time of the 1-month followup, or the programme of the intervention has finished with the client having successfully maintained contact with the service for its duration, then this box should not be checked.

This box should not be automatically checked if the client cannot be contacted for follow-up in item 22; their withdrawal from the service should be treated as independent from their ability to be contacted. (Though there will obviously be cases where a client who 'withdraws from the service' will also be 'not contactable' for follow up, they should be treated separately for analysis purposes.)

25. Has the client smoked at all (even a puff) in the last 2 weeks?

The above question should be asked of all clients who set a quit date and were successfully contacted at the 1-month follow-up. To ensure consistency the question

should be asked exactly as above (inserting 'have you' instead of 'has the client' when speaking directly to them) – using the 'even a puff' phrasing.

As mentioned previously, the criteria used to determine quit success is one which attracts debate, with different organisations proposing different standards. While the criteria used here is not perfect, it is seen as the 'best fit' solution, based on what we know of cessation in the UK at present and in line with international standards.

The source for this criteria is the West et al. clinical guidance – The Russell Standard - referred to previously⁷.

The creators of this criteria explain that a period of 2 weeks was chosen because this was deemed a significant period of time for a former smoker to be classified as not having smoked.

The item design also allows a grace period in recognition of the fact that some smokers initially struggle and may lapse early on in the quit attempt (e.g. in the first couple of weeks), but then manage to stop effectively. It is important to remember that while some clients may not be classified correctly by this criteria (they may have lapsed within the 'last two weeks', but then go on to subsequent success), the best evidence we have suggests that most clients will be assessed effectively by this criteria.

This 2-week period also brings Scotland broadly in line with procedures used in the rest of the UK for measuring 1-month quit rates.

If the client answers 'no' to this question, indicating that they have successfully quit, then a carbon monoxide validation should be taken and subsequent follow-ups should be attempted (3 and 12 months). If the client answers 'yes' to this question, indicating that they have smoked within the last 2 weeks, then they do not need to be followed up again. If, in exceptional circumstances, the smoking status of the client is 'not known' despite being contacted, there is also no need for continued follow-up at 3- and 12-months.

26. CO reading confirms quit?

Services should take carbon monoxide (CO) readings from all clients who self-report having quit at the 1-month follow-up.

If a client answers that they have smoked in the last two weeks to the previous question, it is not necessary to take a CO reading. If, under exceptional circumstances, the follow-up was not conducted in person, then CO readings need not be taken. It is appreciated that CO monitoring may not be possible under certain circumstances, for example in rural or island boards where support sessions and/or follow-ups may have to be conducted by telephone or letter rather than face-to-face. For the purposes of the minimum dataset, CO validation is not required at any other follow-up other than the 1-month point (although services may wish to record CO monitor results at other times if they wish).

⁷ West, R., et al. (2005) Outcome criteria in smoking cessation trials: proposal for the common standard. *Addiction*, 100, 299-303.

CO monitors are an important motivational tool for clients undergoing cessation treatment. Many services routinely use these as way of showing clients how they are improving their health by quitting. CO monitors are also a relatively cheap and easy way of validating that a person is a non-smoker and provide an additional, reliable measurement of short-term cessation rates. Indeed, there can be quite a difference between self-reported and carbon monoxide validated quit rates.

However, the rationale for taking CO readings is not because it is expected that clients are lying about their smoking status, but because it is useful and considered more robust to have information about validated smoking rates in line with those recommended in the Russell Standard.

Service providers may use whichever brand of CO monitor they prefer, and have access to. They should ensure regular calibration and maintenance of their monitors, in accordance with manufacturer's instructions, to provide accurate and consistent readings.

For the purposes of the minimum dataset, a reading of less than 10ppm verifies the client as a non-smoker.

Whilst CO monitor manufacturers' guidance may provide other values for the threshold reading between a smoker and non-smoker, the figure of 10 ppm is one that is (while erring on the side of leniency) extremely unlikely for a non-smoker to exceed, and is supported by current clinical guidance. It is emphasised that services may collect the actual figure from the CO reading, and use it to inform their intervention. E.g. the use of 7 ppm as a 'cut-off' point for pregnant women in order to minimise the likelihood of pregnant women missing out on support provision.

3-Month Follow-Up

A 3-month follow-up is included in the minimum dataset to provide information on medium-term cessation. A high proportion of smokers are known to relapse in the first year of their quit attempt, particularly in the first 6 months. A further advantage of contacting clients at this stage is that it may facilitate further intervention if relapse has occurred.

Who to include in the 3-month follow-up

Services should attempt to follow-up *all clients setting a quit date who had successfully quit at the 1-month follow-up, based on self-report.* If CO validation did not confirm a client's self-reported quit then they should still be followed-up at 3 months. If a client explicitly does not consent to being followed up then they should not be contacted.

When to conduct the 3-month follow-up

The first time at which a client should be contacted is 3 months after their quit date. If they cannot be contacted at this time, a reasonable number of further attempts (e.g. 3 attempts, ideally on different days, at different times, by different methods) should be made within the next 4 weeks. The 3-month follow-up should be completed roughly within 16 weeks of the quit date (depending upon the calendar month). If it has not been possible to contact a client within this time, the individual should be counted as '*lost to follow-up*' for that particular point of contact. This cut-off point helps to promote meaningful and consistent data. Services are encouraged to make note of when follow-ups are due when the quit date is set (as with the 1-month follow-up, the national smoking cessation database can assist in this task by flagging up follow-ups due to be carried out).

How to conduct the 3-month follow-up

It should be ensured that the follow-up questions are asked as described in the following pages. Follow-ups may be conducted in person, by phone, by post or by electronic methods (e.g. by email or text message), depending on the preferences of the service. It is suggested that services try to contact clients by telephone first and if after three attempts (preferably on different days/at different times) the client has not been reached, then a letter should be sent out requesting the follow-up information. Any client who could not be contacted by phone after multiple attempts and who does not reply to a letter should be counted as 'lost *to follow-up*'.

27. Was client successfully contacted for 3-month follow-up?

The first item in relation to the 3-month follow-up is if the client was able to be contacted. The options presented are overleaf:

Yes Please now complete questions 28-29, and verify Pharmaceutical Usage (item 18) is correct

No (Client lost to follow-up) No (Client did not consent to follow-up) No (Client died) Unknown Please now verify Pharmaceutical Usage (item 18) is correct

If the client *was* successfully contacted for follow-up then the date when follow-up took place should be noted in the following question. This is useful to check what time period has elapsed since the quit date and follow-up, and to check it falls within the time period allocated. If a client has been contacted for follow-up, then the remaining two 3-month follow-up questions (*28 & 29*) should then be completed. The client's usage of pharmaceuticals (pharmacotherapies), as taken in *item 18* should be verified here to ensure that the information given on this client is still correct. Item 18 should be updated if the usage has changed (e.g. pharmacotherapies were used for longer than initially planned).

If the client *was not* contacted for follow-up then the reason should be noted by ticking the appropriate box. If the client has not been contacted for follow-up, then their previously given usage of pharmaceuticals (pharmacotherapies) from *item 18* should be verified from service records if possible, and amended if necessary.

Note: Attempts should still be made to follow-up clients at the 12-month stage, even if they could not be contacted at the 3-month stage; the electronic national smoking cessation database will assist in planning this work, as it will flag up for 12-month follow-up those who were not contactable at 3.

28. Date follow up carried out:

The above question should be completed for all clients who were followed up at the 3-month stage. This question allows services to check whether the follow up was carried out within the timescales set to ensure consistency across services within Scotland. If the follow-up was undertaken by letter, this should be the date correspondence was returned.

29. Has the client smoked at all since the 1-month follow-up?

The above question should be asked of all clients who set a quit date and have successfully quit (as measured by self-reported smoking status) at the 1-month follow-up. It should be asked exactly as it is written above (inserting 'have you' instead of 'has the client' if speaking directly to them) and the following options offered:

No Yes, between 1 and 5 cigarettes in total Yes, more than 5 cigarettes Unknown

Not smoking at all, or smoking between 1 and 5 cigarettes since the 1-month follow-up is the criteria by which a client is considered as abstinent at the 3-month follow-up.⁸

This item offers a useful indication of the number of clients who have essentially been abstinent for a prolonged period, but might have had minor lapses at some point. Prior to the introduction of this standard, services may have used different criteria to confirm abstinence at 3 months. The above classification offers some standardisation – either of the first two options above would classify the client as abstinent.

If the client answers '*no*' or '*between 1 and 5 cigarettes in total*' then attempts should be made to follow them up at 12 months. Attempts should also be made to follow-up clients at 12 months who could not be contacted for follow-up at the 3-month stage. If the client reports to smoking more than 5 cigarettes then they do not need to be followed up at 12 month

⁸ West, R., et al. (2005) Outcome criteria in smoking cessation trials: proposal for the common standard. *Addiction*, 100, 299-303.

12-month Follow-Up

Although 1-month and 3-month self-reported quits provide a useful indicator of shortand medium-term success, they are only partially predictive of longer-term cessation.

For this reason a 12-month follow-up is included in the minimum dataset to provide information on longer-term cessation and a better indicator of sustained smoking cessation. The format and process of the 12-month follow-up is very similar to that performed at 3 months.

Who to include in the 12-month follow-up

Services should attempt to follow-up all clients who had successfully quit at the 1month follow-up, based on self-reported data, unless they reported having smoked more than 5 cigarettes at the 3-month follow-up.

If CO validation did not confirm a client's self-reported quit at 1 month then they should still be followed-up at 3 and 12 months. If a client explicitly does not consent to being followed up then they should not be contacted. Attempts should be made to follow-up clients at this point even if they could not be contacted at the 3-month follow-up. The national smoking cessation database automatically flags such clients for follow-up.

When to conduct the 12-month follow-up

The first time at which a client should be contacted is 12 months after their quit date. If they cannot be contacted at this time, a reasonable number of further attempts (e.g. three attempts, perhaps on different days and at different times, or by using different methods) should be made within the subsequent 4 weeks. Follow-ups should be completed within 56 weeks of the original quit date to be considered 'valid'. If it has not been possible to contact a client within 56 weeks from their quit date, the individual should be counted as '*lost to follow-up*'. This cut-off point helps to promote meaningful and consistent data. Services are encouraged to make note of when follow-ups are due when the quit date is set (as with the 1-month, and 3-month follow-ups, the electronic national smoking cessation database will assist in this task by flagging follow-ups due to be carried out).

How to conduct the 12-month follow-up

Please refer to 3-month guidance on page 25 – the procedures for 12-month followup are exactly the same.

30. Was the client successfully contacted for 12-month follow-up?

The first item in relation to the 12-month follow up is if the client was able to be contacted for the 12-month follow-up or not. The options presented are as below:

Yes

Please now complete questions 31-32

No (Client lost to follow-up) No (Client did not consent to follow-up) No (Client died) Unknown **Do not complete any further guestions**

The format for response here is the same as with the 3-month follow-up, with the exception that verification of pharmaceuticals (pharmacotherapy) use is not necessary (it is assumed that the use of pharmacotherapies will have ended before 12 months).

31. Date follow up was carried out:

If the client *was* successfully contacted for follow-up then the date when follow-up took place should be noted here. If the follow-up was undertaken by letter, this should be the date correspondence was returned. This is useful to check what time period has elapsed since the quit date and follow-up, and to check it falls within the valid time period for 12-month follow-up.

32. Has the client smoked at all since the 1-month follow-up?

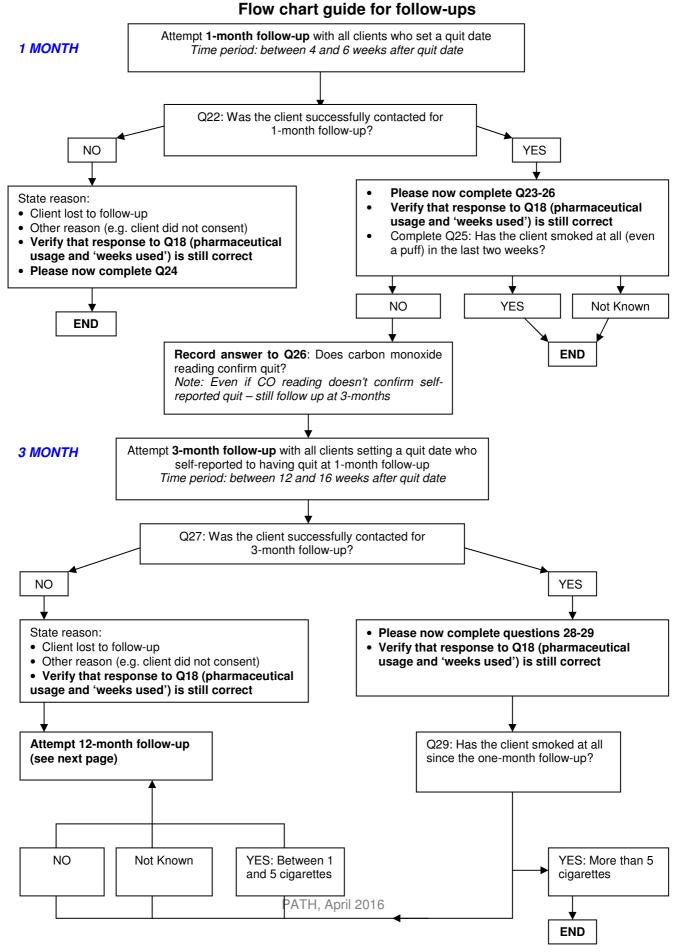
The above question should be asked of all clients who set a quit date and had successfully quit (self reported) at the 3-month follow-up, or if they were not able to be contacted at the 3-month follow-up. It should be asked exactly as it is written above (inserting 'have you' instead of 'has the client' if speaking directly to them) and the following options offered:

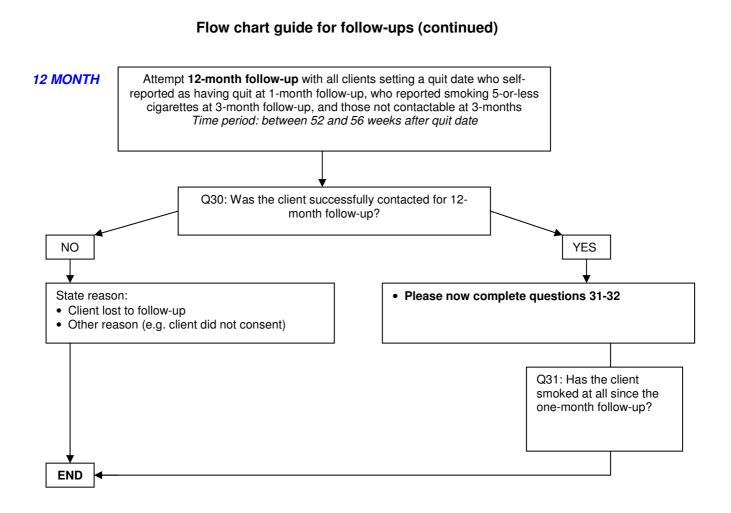
No Yes, between 1 and 5 cigarettes in total Yes, more than 5 cigarettes Unknown

As with the 3-month follow-up criteria, and with the same rationale, either of the first two responses in the list above would classify the client as abstinent at the 12-month point.

Follow-up on this case would now be complete.

A flow chart summarising the procedures for the 1, 3, and 12-month follow-ups is given on the following pages.







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PATH is a joint initiative between ASH Scotland, NHS Health Scotland and the Scottish Government to reduce the prevalence of tobacco use in Scotland. Action on Smoking & Health (Scotland) (ASH Scotland) is a registered Scottish charity (SC 010412) and a company limited by guarantee (Scottish company no 141711).