



# Smoking Cessation Services in Scotland

Recommendations for the future development of Scottish Smoking Cessation services:

Data Collection, Monitoring & Evaluating, Information Management and Essential Resources

Please note that the [minimum dataset](#) and [best practice guidelines](#) for data collection given in this document are DRAFT versions. These were superseded in August 2004 by the document '*The Minimum Dataset for Scottish Smoking Cessation Services: Final Version and Guidelines for Use*'.

This updated document is available on the ASH Scotland website:  
<http://www.ashscotland.org.uk/inequalities/minimumdataset.pdf>

**Updated December 2004**

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## **Background to 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'<sup>1</sup>, and in subsequent policy documents, including Scotland's 1999 White Paper 'Towards a Healthier Scotland'<sup>2</sup>. Funded by the Scottish Executive and managed by ASH Scotland, PATH will, with key partners, develop and roll out best practice across key areas of training, data collection, evaluation, prevention and cessation.

What is PATH doing?

- Developing national training standards, a national training strategy and training resources for cessation work.
- Managing a support fund of £300,000 per annum, which will provide support for creative local pilot initiatives in smoking cessation work with high risk groups, that reflect the White Paper priorities
- Making recommendations on data collection and evaluation of smoking cessation services, based on good practice
- Supporting the development of information and research strategies linked to the White Paper

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## **Background to Smoking Cessation Services in Scotland**

Tobacco use is the single biggest preventable cause of ill-health and premature death in Scotland and a major cause of inequalities in health. In Scotland 13,000 people die every year from tobacco-related diseases, including heart disease and many cancers<sup>3</sup>. Recent evidence has also confirmed the serious health risks of passive smoking<sup>4</sup>.

Scotland has an estimated 1.4 million adult smokers<sup>5</sup>. Results from the 1998 Scottish Health Survey give cause for concern about adult smoking rates. These suggest that one more than one third (34%) of the adult population in Scotland smoke cigarettes<sup>6</sup>. There is a strong correlation between smoking and deprivation, with the same survey revealing that 49% of men and 43% of women from the most deprived areas of Scotland are smokers. Those on low incomes are more likely to smoke cigarettes and smoke more cigarettes per day on average.

In the late 1990s The NHS in Scotland spent an estimated £140 million per annum on hospital treatment for diseases caused by tobacco<sup>7</sup>. Scottish Executive economists suggest that at current prices this would amount to over £200 million. Reducing smoking rates will lead to health gains that in the long term will reduce smoking related health care costs. Few medical interventions of any kind have the potential of smoking cessation to deliver such cost-effective health gains. Calculations on the cost-effectiveness of a range of smoking cessation interventions estimate that costs per life year gained range from £21 to £711 when costs to the NHS and smokers are taken into account<sup>8</sup>. With 7 in 10 smokers wanting to quit<sup>9</sup>, the time is right to focus on smoking cessation interventions.

Provision of smoking cessation services is a core element of a comprehensive approach to tobacco control and is necessary for improving the health of Scotland's population. The 1998 White Paper 'Smoking Kills'<sup>1</sup> set out a national smoking cessation strategy for the UK, including the provision of NHS Scotland smoking cessation services. In 1999/2000, a total of £3million over three years was allocated to Scottish NHS Health Boards for the development of these services and the provision of nicotine replacement therapy (NRT).

In 1999 the Scottish Executive reiterated the commitment to reducing smoking in its White Paper on Health<sup>2</sup>, which set new targets for the reduction in smoking prevalence in Scotland. Targets were set for reducing adult smoking (from 35% in 1995, to 33% in 2005 and 31% in 2010), smoking prevalence among 12-15 year olds (from 14% in 1995, to 12% in 2005 and 11% in 2010), and smoking in pregnancy (from 29% in 1995, to 23% in 2005 and 20% in 2010). A commitment was given to the provision of smoking cessation treatment as part of a comprehensive tobacco control strategy. Smoking cessation was also identified as a priority for investment under the new Health Improvement Fund (HIF), which invested an additional £104m from tobacco tax revenues over a four-year period for improvements

in public health. Around £750,000 per year was invested directly in cessation services in Scotland through HIF monies.

More recently, the 2003 White Paper, 'Improving Health in Scotland – The Challenge' lists tobacco as a major risk factor, and a focus for activity under each of its four themes – The Early Years, Teenage Transition, The Workplace and Communities. In addition, the ASH Scotland and NHS Health Scotland joint document, 'Reducing Smoking and Tobacco-Related Harm - A Key to Transforming Scotland's Health', finalised in July 2003, and which will be published later in 2003, will form the basis of a Scottish Executive tobacco action plan in which cessation will feature prominently. The revised Smoking Cessation Guidelines for Scotland, also to be published by ASH Scotland and NHS Health Scotland later in 2003, are intimately linked to all of the developments outlined above and throughout this document.

As a result of the aforementioned papers and policies, there has been a rapid development of smoking cessation services in Scotland in recent years. There are now smoking cessation services running in each health board area in Scotland, working to support the achievement of the targets set out above. It is important to monitor the efficacy of smoking cessation services and to find out how many smokers are being helped to quit. Presently there is immense diversity in the monitoring and evaluation practices of smoking cessation services in Scotland. The scope and detail of data collected, and the ways in which this information is used, varies greatly.

This report outlines PATH's recommendations for a co-ordinated and systematic approach towards data collection for the purposes of monitoring and evaluation of Scottish smoking cessation services. These recommendations will have a positive impact if they are adopted in their entirety. Their benefit will also be maximised within an environment where smoking cessation services are resourced at a realistic level to address local need, and where they enjoy the stability of the long-term funding required to facilitate their longer-term strategic planning and development.

The recommendations are based on discussions with a range of smoking cessation professionals whom PATH consulted between July 2002 and February 2003. The recommendations have also been developed with the guidance and advice of a number of key partners and external agencies, listed below.

## **Key partners involved in the development of the recommendations**

### **PATH Information and Evaluation Working Group**

Amanda Amos,	University of Edinburgh
Linda Bauld,	University of Glasgow
Jim Chalmers,	ISD, NHS Scotland Common Services Agency
Sheila Duffy,	ASH Scotland
Sally Haw,	NHS Health Scotland
Peter Knight,	ISD, NHS Scotland Common Services Agency
Jane Parkinson	NHS Health Scotland
John Taylor	Fife Primary Care NHS Trust

### **Mapping Exercise Participants**

Nancy Barr	Hamilton, Blantyre and Larkhall LHCC
Gillian Bruce	Forth Valley South LHCC
Anne Bryce	Argyle and Clyde Health Board
Helena Connelly	West Lothian Healthcare NHS Trust
Mary Anne Crook	Orkney Smoking Cessation Service
Fiona Dunlop	Greater Glasgow Smoking Concerns
William Edwards	Angus LHCC
Elaine Grant	Ayrshire and Arran Primary Care Trust
Trish Grierson	Dumfries and Galloway Health Board
Kate Johnstone	Forth Valley LHCC
Aileen Laird	Orkney Smoking Cessation Service
Janine Langler	Grampian Health Promotions
Roisin Lynch	West Renfrewshire LHCC
Wendy Lynn	Borders Primary Care NHS Trust
Judith Mann	South Central Edinburgh LHCC
James McAteer	Dunfermline LHCC
Tina McDonald	Western Isles Health Board
Sheila McFadyen	Airdrie LHCC
Kate McGhee	Wishaw, Shotts, Newmains and Harthill LHCC
Agnes McGowan	Greater Glasgow Smoking Concerns
Sheila Menzies	South Central Edinburgh LHCC
Penny Millsopp	Shetland Health Board
Fiona Moore	Lothian Health Board
Maxine Moy	West Fife LHCC
Brian Pringle	West Lothian Drug and Alcohol Service
Hania Proudfoot	Coatbridge LHCC
Anne Reilly	Hamilton, Blantyre and Larkhall LHCC
Audrey Smith	Shetland Health Board
Cathy Steer	Highland Health Board

## **Methodology**

Between July 2002 and February 2003 PATH conducted a mapping exercise to find out more about data collection, data storage, evaluation strategies and other such aspects of smoking cessation work across Scotland. Smoking cessation professionals from twenty-four smoking cessation services (with at least one representative from each Health Board Area) participated in the mapping exercise.

A member of the PATH team conducted face-to-face interviews with the person(s) responsible for the day-to-day management and provision of specialist smoking cessation services in order to complete a detailed eight-part questionnaire covering the following topics:

- Respondent's job description and service details
- Funding the service
- Staffing the service
- Data collection (questionnaires/forms used by service were also gathered)
- Data management
- Procedures for data analysis, evaluation and monitoring
- Work with priority groups
- Attitudes towards ways of further developing services

The results from the questionnaires were entered into a spreadsheet to facilitate analysis. The spreadsheets were rigorously examined to compare and contrast aspects of service provision under various themes. Given the relatively small number of services surveyed, robust statistical analysis of the data was not possible, although basic calculations of the numbers of services that followed a certain practice or procedure were carried out. Most analysis was therefore qualitative in nature.

The mapping results showed great variation in service provision and practices. These recommendations have tried to take this diversity into account. A short report on current evaluation and monitoring practices of smoking cessation services in Scotland is available from PATH on request.

In addition to the primary data gathered through the mapping exercise, reliable secondary sources were used to guide best practice recommendations. Literature reviews were conducted to find relevant research evidence and existing smoking cessation guidelines from across Britain were consulted. These recommendations are framed to reflect Scottish needs and, where possible, provide continuity with the rest of the UK.

## **Report Aims and Scope**

PATH was tasked with making recommendations on a systematic process for monitoring and evaluating Smoking Cessation Services in Scotland. This report focuses on recommendations related to data collection, based on best practice.

### Objectives:

- To define a minimum dataset, comprising the essential information on clients to be gathered by smoking cessation services.
- To outline additional data that services may wish to collect.
- To offer standardised procedures for measuring cessation outcomes.
- To recommend resources required to make these proposals feasible, notably an integrated information management system, which will assist in the day-to-day running of smoking cessation services and facilitate the collection of data for audit purposes.

These will help to ensure consistency and validity of data collected for the purposes of national statistical monitoring and for reporting to local stakeholders and policy makers.

### This document does NOT consider:

- Issues related to smoking cessation training. PATH has been asked to develop quality standards for the content and delivery of training for both brief advice to stop smoking and for specialist smoking cessation support. These will be covered in a separate report.
- Prevention of smoking uptake.
- Fiscal and legislative interventions for tobacco control.
- Recommendations on how to implement clinical interventions or offer guidance on how to target different groups of smokers.

Although these are outwith the frame of reference of this report, we recognise that they are vital elements in any strategy to reduce smoking prevalence. Smoking cessation services should be integrated into a wider strategy on tobacco control.

## Summary of recommendations

This table below summarises the key recommendations that are detailed in this report and action required by pertinent organisations and professionals to implement these:

RECOMMENDATION	ACTION
<p><b>A nationwide minimum dataset:</b> A minimum set of client data to be collected by smoking cessation services, to improve the quality of national monitoring information is proposed.</p>	<ul style="list-style-type: none"> <li>• <b>Scottish Executive/Health Boards:</b> allocate revenue to cover additional costs (staff and administrative) resulting from new data collection arrangements.</li> <li>• <b>PATH:</b> develop a strategy for piloting and roll-out of the minimum dataset, and for training in its use.</li> <li>• <b>Smoking Cessation Services:</b> begin to use the minimum dataset under guidance from PATH and Health Boards.</li> </ul>
<p><b>Best practice guidelines for data collection:</b> A comprehensive set of guidelines to help smoking cessation services gather data on their clients and to increase standardisation of nationwide data has been devised.</p>	<ul style="list-style-type: none"> <li>• <b>Scottish Executive:</b> commission further research into long-term success rates of smoking cessation services and into clients who do not attend appointments</li> <li>• <b>PATH:</b> offer guidance to services concerning the best practice guidelines.</li> <li>• <b>Smoking Cessation Services:</b> put guidelines for data collection into practice.</li> </ul>
<p><b>A nationwide data management system:</b> A number of features of a computerised data management system, to facilitate collection of the minimum dataset and enhance the day-to-day operation of smoking cessation services, have been identified.</p>	<ul style="list-style-type: none"> <li>• <b>Scottish Executive:</b> allocate revenue for the development and maintenance of a data management system.</li> <li>• <b>PATH:</b> work towards developing a viable data management system, in consultation with appropriate professionals.</li> <li>• <b>Smoking Cessation Services:</b> begin to use the new data management system.</li> </ul>
<p><b>Minimum standards for staff and resources:</b> The essential resources (staff, salaries, contracts, training, equipment) required to enable smoking cessation services to meet demand and to implement the recommendations in this report have been identified. Most significantly we recommend the creation of a new post in smoking cessation teams to take on some of the extra work resulting from the new data collection requirements.</p>	<ul style="list-style-type: none"> <li>• <b>Scottish Executive/Health Boards:</b> provide financing to ensure that smoking cessation services are adequately resourced and staffed on a permanent basis. In particular revenue should be allocated for expanding smoking cessation teams and for appropriate training.</li> <li>• <b>PATH:</b> develop a training strategy and standards for smoking cessation work</li> <li>• <b>Smoking Cessation Services:</b> ensure that all members of smoking cessation teams receive appropriate training throughout their employment.</li> </ul>
<p><b>Enhancing partnership work:</b> Various strategies to improve communication between those working in the fields of smoking cessation, and more widely in tobacco control and health, are acknowledged.</p>	<ul style="list-style-type: none"> <li>• <b>Scottish Executive:</b> commission research into inappropriate referrals to smoking cessation services (e.g. from GPs)</li> <li>• <b>PATH:</b> continue to develop relationships with pertinent individuals and organisations, investigate establishing a smoking cessation practitioners' network</li> <li>• <b>Smoking Cessation Services:</b> continue to develop relationships with pertinent individuals and organisations</li> </ul>

## Recommendations

### 1. The development and use of a nationwide minimum dataset

Please note that the minimum dataset and best practice guidelines for data collection given in this document are DRAFT versions. These were superseded in August 2004 by the document '*The Minimum Dataset for Scottish Smoking Cessation Services: Final Version and Guidelines for Use*'.

This updated document is available on the ASH Scotland website:  
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#### 1.1 *The minimum dataset*

It is important that services are monitored using standard definitions of key terms and standard procedures. This increases consistency across services, where possible, and increases the validity of monitoring and evaluation information. Health boards are required to record relevant information on their smoking cessation services and to assess their performance against targets set out in the White Paper 'Towards a Healthier Scotland'<sup>2</sup>. However, at present figures on outcomes can be difficult to interpret and compare because services are using different criteria.

We therefore recommend the use of the attached minimum dataset, which was developed in consultation with smoking cessation professionals across the country and takes into account, where possible, the data that services are currently collecting. The minimum dataset represents the *essential information to be collected for each client for national statistical monitoring of specialist smoking cessation services*. It is anonymised data which will be sent to a central research team for audit purposes. Any personal details or possible identifiers would be removed before sending on.

The minimum dataset is outlined in Table 1, below. It contains information that was identified as helpful within Scotland, while featuring similar core information to the existing English and Northern Irish minimum datasets. The dataset will facilitate comparisons of smoking cessation services both within Scotland and with the rest of the UK.

A list specifying possible responses to the minimum dataset questions is outlined in Appendix 1. This Appendix also includes a (draft) protocol providing detailed guidance for practitioners on completion of the minimum dataset.

**Table 1 The Minimum Dataset**

Mandatory fields to be gathered for each client setting a quit date. Please refer to Appendix 1 for further details on question wording and responses.

	<b>Item</b>	<b>Reason</b>
<b>A</b>	<b>Client Demographics</b>	
1	Health Board Area	To measure uptake by area
2	LHCC (if applicable)	
3	Unique client identifier	Anonymised method for linking data, particularly for follow-up information
4	Full Postcode	To measure uptake by area and proxy measurement for socio-economic status - postcode & electoral ward information used to map deprivation categories, (lower income groups a priority group)
5	Date of Birth	To measure uptake by different age groups (young people a priority group with national targets, older smokers also a priority)
6	Gender	To measure uptake of services by men and women
7	Pregnant (if female) at quit date	To measure uptake by pregnant women (priority group within national targets)
8	Ethnicity	To measure uptake by different ethnic groups
9	Entitlement to free prescriptions	Additional measurement of lower income (postcode not always reliable as measure of socio-economic status, especially in rural or island areas).
10	Entitlement to income support	Additional measurement of lower income (entitlement to free prescriptions not always reliable as measure of lower income - some people in receipt of free prescriptions are not on lower income)
	<b>Tobacco Use &amp; Quit Attempt</b>	
11	Number of cigarettes smoked per day?	To measure client's tobacco use and level of addiction
12	How soon after waking does client usually smoke their first cigarette?	To measure client's tobacco use and level of addiction
13	How easy or difficult would client find it to go without smoking for a whole day?	To measure client's tobacco use and level of addiction
14	How many times client has tried to quit smoking in the past year?	To measure number of recent unsuccessful quit attempts
15	Quit date	Date from which to measure follow-ups (only clients setting quit date included for purposes of national monitoring)
16	Has client received NRT and/or Bupropion (Zyban)?	To measure number of clients using these medications, to give an indication of their impact on outcomes and to provide context to present quit attempt

**Table 1 (cont.) The Minimum Dataset**

17	Type of intervention (group, individual).	To see what sort of interventions are common and to compare outcomes
<b>C</b>	<b>Outcomes of Intervention</b>	
18	Self-reported smoking status at 1 month follow-up	To assess short-term success of cessation treatment
19	Results of carbon monoxide monitor validation at 1 month follow-up	Additional measurement to assess success of cessation treatment
20, 21	Self-reported smoking status at 3 month follow-up	To assess longer-term success of cessation treatment
22, 23	Self-reported smoking status at 12 month follow-up	To assess longer-term success of cessation treatment

1.2 *Additional data for local purposes*

We acknowledge that local services operate in different and diverse ways, and strongly recommend that services collect further information from clients at initial assessment and follow-ups. Such information is valuable to guide treatment and assist in localised service planning and monitoring, either at the level of the individual service, LHCC (local health care co-operative) or Health Board.

There are many items of core data that need to be collected by smoking cessation services for their own use, but which are *not* required for anonymised national monitoring. Such items include client's name, address, and telephone number, which are necessary to identify clients for follow-up. Information concerning clients' GP and medical history also needs to be collected for use at service level.

We also recommend finding out more details about clients' background, tobacco use and motivation to stop at the beginning of their contact with the service. Likewise, we encourage services to find out additional information at follow-ups about the outcomes of intervention, (e.g. changes in client's tobacco-related knowledge, attitude and behaviours). This type of information will be useful in determining the number of unsuccessful quitters who have made positive changes to their tobacco use since treatment, in order to provide a more general context to service achievements (see section 2.5).

In addition, we strongly recommend that services offer clients the opportunity to evaluate the service, for example by filling in a questionnaire relating to aspects of service provision (e.g. about their experience of trying to quit, their overall satisfaction with the service, their thoughts on staff, materials, course content, location, and the length, structure and number of sessions etc). This kind of information is useful for evaluating the strengths and weaknesses of the service, and for guiding future service developments.

Examples of additional data that could be collected are summarised in Table 2, below. We are not suggesting that services should gather all of this data, this is *optional* depending on what the individual service wants to know. Indeed, if there were additional appropriate data that services wish to collect which are not mentioned here, then they would be encouraged to do so. The examples given below are for *guidance only and are neither prescriptive nor exhaustive*.

It is worthwhile clarifying that the aim of this document is to recommend questions for the purposes of national evaluation relating specifically to clients and the outcome of their quit attempt. We are not making recommendations here on other information that services may be providing to management for audit (e.g. staffing levels, funding and costs, waiting lists, number of enquiries, drop-out rates). However, we recognise that these aspects of service provision are important and encourage services to continue to record such data.

**Table 2 Examples of Additional Data for Local Level**

Core Data (*essential* for the service, but not necessary for anonymised national statistical monitoring)

Item	Suggestions/Examples	Reason
Client contact details	- full name, address, telephone number(s)	To identify client, for follow-up activities
Medical history	- medical conditions/illnesses - medications taken - allergies/reactions - pregnancy related: breastfeeding, planning to conceive	For medical records, to guide prescribing of NRT/Bupropion (Zyban)
GP details	- name of doctor/practice, address, telephone number	To inform GP of client's treatment (if client consents)

Optional Data (*useful* for the service, but not necessary for national statistical monitoring)

Item	Suggestions/Examples	Reason
Tobacco Use	- how long client has been smoking - what smoked (cigarettes, hand-rolled, pipe tobacco)	To guide service provision: to assess level of addiction
Motivation to quit	- reasons for wanting to quit (open question or list of possibilities) - 'stage of change'	To guide service provision, to assess client's motivation and suitability for treatment

**Table 2 Examples of Additional Data for Local Level (cont.)**

<b>Item</b>	<b>Suggestions/Examples</b>	<b>Reason</b>
Previous quit attempts	<ul style="list-style-type: none"> <li>- dates of previous/last attempt(s)</li> <li>- previous use of services/support</li> <li>- previous experience of NRT and/or Bupropion (Zyban)</li> <li>- why previous quits unsuccessful</li> </ul>	To guide service provision, to assess client's motivation and suitability for treatment
Follow-up/ Behavioural change	<ul style="list-style-type: none"> <li>- stopped smoking indoors/in car</li> <li>- no longer smokes in front of children/other non-smokers</li> <li>- has first cigarette later in day</li> <li>- no longer wakes to have cigarette in the night</li> <li>- stopped longer than before</li> <li>- made them think about trying again in future</li> </ul>	To assess secondary outcomes, particularly if client has not quit
About the cessation service	<ul style="list-style-type: none"> <li>- professional providing the intervention (name, occupation)</li> <li>- setting of intervention</li> <li>- source of referral/how client found out about service</li> <li>- additional CO readings</li> </ul>	To assess success of cessation service, to guide future service provision
Other	<ul style="list-style-type: none"> <li>- who client lives with (other smokers, children)</li> <li>- if client smokes at work</li> <li>- support networks</li> <li>- client comments/evaluation of service</li> </ul>	To provide further information on client situation and context of quit, to guide future service provision

### 1.3 *Guidance and Training*

It is recommended that full guidance be provided for the use of the minimum dataset to ensure that complete and accurate information is collected for the purposes of national monitoring. It is important that each aspect of the minimum dataset is defined and procedures for data collection are clarified to smoking cessation professionals. It is also essential that smoking cessation staff are aware of patient confidentiality issues to guarantee that all data is processed in accordance with the 1998 Data Protection Act. Likewise, staff would also need to be trained on how to use any computerised data management systems which may be introduced to complement the new minimum dataset (see section 3).

Training could take the form of written guidelines and supplementary workshops. Initial training could be provided to co-ordinators who could then roll out guidance at team meetings to other smoking cessation workers. Training on the minimum dataset would also need to be integrated into initial training received by all those new to smoking cessation.

An outline of best practice guidelines for smoking cessation services is presented in section 2 and a (draft) protocol providing detailed guidance for completion of the minimum dataset is attached as Appendix 1. It should be noted that these are for illustrative purposes only and may require further modification after the dataset has been piloted and to fit with the complete data management package once it has been developed.

#### 1.4 *Piloting and roll-out*

We recommend that the minimum dataset be piloted in a variety of services across Scotland within the next six months, to uncover any difficulties involved in gathering the required data. Depending on the issues identified, the minimum dataset will then be rolled-out for use by smoking cessation services throughout all Health Board areas during the following six months. The minimum dataset fields outlined above may therefore be subject to change.

Most services already have their own client registration forms and these should be adapted to ensure that the information required by minimum dataset is included. If preferred, a standard form or template for services to use could also be provided. Co-ordinators and practitioners need to ensure that they collect the full set of client information required by the minimum dataset. Services should continue to collect any additional information that they see as necessary.

## 2. **Best practice guidelines for data collection**

Please note that the minimum dataset and best practice guidelines for data collection given in this document are DRAFT versions. These were superseded in August 2004 by the document '*The Minimum Dataset for Scottish Smoking Cessation Services: Final Version and Guidelines for Use*'.

This updated document is available on the ASH Scotland website:  
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At present figures on success rates are difficult to interpret and compare because services are using different criteria to measure the number of clients helped. To increase standardisation and facilitate data gathering the following best practice guidelines are offered. Greater detail relating to all the following points is provided in the (draft) protocol for use of the minimum dataset in Appendix 1.

#### 2.1 *Clients to be included in the monitoring*

All clients who set a quit date should be included in the monitoring. This would put Scotland in line with standardised monitoring

procedures already used in England and Northern Ireland. It is expected that most clients who receive counselling will go on to set a quit date. Those who access services but do not go on to set a quit date are outside the scope of the central monitoring, even if they have received counselling. We considered the inclusion of such clients in the monitoring but concluded it would be difficult to obtain useful data.

Nonetheless, it is recognised that some clients receive counselling but do not set a quit date and that they represent a significant expenditure of effort and resources. While information on clients who receive counselling but do not set a quit date is not to be included in national monitoring, services are *strongly encouraged* to collect additional information on such clients for the purposes of local monitoring, evaluation and service planning (as suggested in 1.2).

## 2.2 *End point from which to measure follow-ups*

Our recommendation to measure follow-ups *from the time of the quit date* brings Scotland in line with standards already implemented in the rest of the UK. Measuring from the quit date also fits with guidance for the use of Nicotine Replacement Therapy and Bupropion (Zyban)<sup>i</sup>, and with the practices of many smoking cessation services in Scotland<sup>ii</sup>.

Other end points were considered, such as the start or end of the intervention. The first was not chosen as this could include many people who contacted the service but did not continue with a quit attempt. The latter was deemed to be too vague and difficult to define, particularly as some clients may still receive counselling long after they have actually quit.

## 2.3 *Follow-up points*

Research suggests that the best approach for documenting success rates in smoking cessation interventions is to report multiple measures of abstinence<sup>10</sup>. We therefore recommend that the minimum dataset records information on both short-term and longer-term quit rates, based on *self-reported smoking status at three periods following a client's quit date: 1 month (4 weeks), 3 months and 12 months* (see point 2.4, below). We also recommend *carbon monoxide monitor validation at the 1-month follow-up* as standard and at other follow-ups if desired by the service (see point 2.5, below). All clients setting a quit date should be followed-up, either face-to-face, by telephone or post.

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<sup>i</sup> Manufacturers guidance for use of Zyban recommends that a target stop date (quit date) is set within first 2 weeks of smoking cessation therapy. NRT should only be used when a client has actually stopped smoking.

<sup>ii</sup> For example, many smoking cessation programmes use a group-based approach to smoking cessation of 6-7 weeks duration. Clients are encouraged to set a quit date for the week 3 of the course, meaning that the end of the course is 1-month post-quit date.

Our recommendations to follow-up clients at 1 month (4 weeks) and 12 months would bring Scotland in line with procedures already instigated in England and Northern Ireland. They are also based on findings from the mapping exercise and literature review. The approaches we have adopted are in line with those advocated in an article by the Society for Research on Nicotine and Tobacco (ibid):

- Trials of smokers willing to set a quit date should tie follow-ups to the quit date.
- Short-term follow-ups should report abstinence at four weeks (i.e. equivalent to 1 month).
- Verification of self-reported quit rates by carbon monoxide breath monitors is recommended if possible.
- Abstinence rates at 12 months should also be reported as a more stringent measurement of success.

Although 1-month, self-reported quit rates provide a useful indicator of initial success, they are not sufficient to predict longer-term cessation<sup>11,12</sup>, particularly as substantial relapse occurs in the first year after the quit date. Indeed, the World Health Organisation defines former smokers as those who have not smoked in the last year. For this reason we advocate following clients up at 12 months.

Indeed, we also propose that the Scottish Executive commissions further research into longer-term success rates of smoking cessation services. Further research is needed to look at bio-chemically validated quit rates after one year (e.g. by following-up a proportion of clients using carbon monoxide monitors to find out the difference between self-reported quit rates) and to look at success rates in the longer term (e.g. after two, three or more years). This would be best managed and funded nationally, rather than at a local level.

We feel that following-up at 3 months is also a constructive approach. Not only does this provide an intermediate criterion for success<sup>13</sup>, but an added advantage of contacting clients at this stage is that it could facilitate further intervention if relapse has occurred and is a useful way of checking clients' contact details are still correct.

If after reasonable attempts (we suggest three to five), the client has not provided information for follow-up, they should be recorded as 'lost to follow-up' for that particular point of contact. This will provide a more accurate reflection of numbers of clients who are and are not smoking. Previously service users who could not be contacted were often considered to have relapsed, although this is not necessarily the case. Further guidance on follow-ups is included in the draft protocol for use of the minimum dataset (Appendix 1).

To make this recommendation practical we suggest that the Scottish Executive facilitates the Health Boards in creating a new post within smoking cessation teams (which we have termed 'smoking cessation officers') whose remit will include, amongst other things, conducting the longer-term follow-ups (see section 4.6). Services will also require supplementary financial resources to cover the costs accrued by additional follow-ups, for example for phone calls, printing letters and postage.

#### 2.4 *Defining a successful quit*

Based on existing research evidence and best practice guidelines multiple measures of abstinence should be reported<sup>9,12</sup>. All clients are to be followed-up at three points: 1 month, 3 months and 12 months *after* their quit date. Self-reported quit rates are used at all points. Although some experts argue that self-reporting may overestimate numbers of non-smokers, especially if the respondent feels under pressure from the enquirer to report that they do not smoke, self-reporting is a practical way of measuring smoking rates when it is difficult or costly to obtain a biochemical validation<sup>iii</sup>. Validation by CO breath monitor should also be recorded at the 1-month follow-up, see point 2.5, below.

At each follow-up point the client should be counted as having successfully quit smoking if they have *not smoked at all in the last two weeks*. An additional question should also be asked at the 3-month and 12-month follow-ups to find out if the client has *smoked less than five cigarettes since the time of the 1-month follow-up*. These questions offer a straightforward way of gathering multiple useful measurements of the success of smoking cessation services. (See Appendix for more details).

At the 1-month follow-up, the first question obtains a measurement of short-term quit rates, whilst offering a grace period in recognition of the fact that some smokers may lapse early on in the quit attempt, before managing to quit. A two-week grace period when measuring short-term abstinence is advocated by the Society for Research on Nicotine and Tobacco<sup>9</sup> and would also bring Scotland approximately in line with procedures used in the rest of the UK.

At the 3-month and 12-month follow-ups, the first question gives a measurement of point prevalence smoking rates – in other words smoking rates during a 2-week window of time. This offers a useful indication of the number of clients who are abstinent at a given point

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<sup>iii</sup> Velicer, W.F. et al. 1992 'Assessing outcome in smoking cessation studies' *Psychological Bulletin*, Vol. 111 (1), pp23-41

in time. The second question offers a measurement of prolonged abstinence – smoking rates over a longer period of time. This counts as successes people who are essentially abstinent but might have had minor lapses at some point.

## 2.5 *The use of carbon monoxide (CO) monitors*

Carbon monoxide breath monitors are an important motivational tool for clients undergoing cessation treatment. They are also a relatively cheap and easy way of validating smoking status. We strongly recommend that CO validation is attempted at the 1-month follow-up. CO validation is not essential at later follow-ups, but services may wish to record CO monitor results at other times if they wish for their own purposes.

It is appreciated that CO monitoring may not be possible in exceptional circumstances, for example in rural or island boards where follow-ups have to be conducted by telephone or letter. The minimum dataset will ask whether CO validation was attempted at follow-up and will record the outcome of the test. Further guidance on use of CO monitors is included in the draft protocol for use of the minimum dataset (Appendix 1)

## 2.6 *Other measurements of a successful cessation outcome*

It is acknowledged that in addition to quit rates, many services also judge their effectiveness by additional measures, for example by recording positive changes to smoking behaviours or attitudes towards smoking. It is recommended that services continue to collect such information for the purposes of service monitoring and development at the local level, although these are *not* essential for national statistical monitoring (see section 1.2).

## 2.7 *Data Protection and Ethics Committees*

Our consultation revealed that some smoking cessation professionals were anxious about data protection legislation and ethical issues relating to data collection for audit and research purposes. Brief guidance on data protection and research ethics will be included in the protocol for use of the minimum dataset (Appendix 1).

It is worth noting that broadly analogous data collection arrangements are now well established around the country in relation to drug misuse and are also in development for clients of local alcohol services. Likewise, a similar minimum dataset for monitoring smoking cessation services in England is already in place.

### **3. The development and use of a nationwide data management system**

3.1 We recommend the introduction of a nationwide data management system, to complement the nationwide minimum dataset outlined in section 1.1. After extensive consultation with smoking cessation professionals, a number of features within this system have been identified that would enhance efficiency of service provision on a day-to-day basis. These features are outlined below.

#### *3.2 An easy to use client database*

A user-friendly database facility is required to record information on clients using the service and to store these records securely. The database would store client data for practical use, the minimum dataset information and any other details required by the service. Desirable features include:

- Flagging up of mandatory fields
- Flexibility for users to add and amend non-mandatory fields
- Ability to export data to/from commonly used packages
- Secure submission of anonymised minimum dataset items to a central monitoring team

#### *3.3 A facility for having GP/other health professionals' referral information sent on via computer*

This would benefit smoking cessation professionals and other health professionals, because referrals would be received instantly, saving both time and administration involved in alternative methods that are currently used. Two-way communication would be increased as the system would enable those working in smoking cessation to forward information on to other health professionals, and vice versa. Ultimately, enhanced communication between services and other health professionals would help to ensure that individuals who want, or need to give up smoking, are given the support that is most appropriate to their individual situation.

This facility could be optional for services to install, as smaller services may currently see a majority of self-referred clients. As services expand, we envisage that this optional feature would become increasingly used by such services, in order to maximise efficiency of day-to-day service provision. Our consultations suggest that this facility would already be very beneficial to larger smoking cessation services.

For such a system to work efficiently it needs to be practical and relevant for both parties using it. It is therefore desirable that GPs and

other health professionals are consulted to find out how such a system would benefit them (see sections 3.10 and 5.6).

A number of factors need to be taken into account when developing an appropriate information management technology system. It is acknowledged that any referral information sent by computer will have to comply with Data Protection guidelines and that computerised referrals would have to be safeguarded. To facilitate usage it would be desirable for the system to be compatible with the GPASS computerised data management system that is currently used by about 84% of GP practices in Scotland and with other primary care IT systems. However, the system would also have to work with smoking cessation services that are outwith the NHS.

#### 3.4 *Computer-based report templates that are stored within the system for services to use as a basis for quarterly/annual report writing*

Computer based report templates would be a useful feature to assist with the completion of ad hoc reports and quarterly and/or annual commentaries. This would be a cost and time effective addition, as services would spend less time compiling and developing reports from scratch. The system would ideally enable information to be inserted directly from the database, and thus detailed reports could be compiled more efficiently than to date.

We envisage that the sort of reports that might be required include:

- Number of clients accessing service, setting a quit date, drop outs, do not attends
- Number of clients from specified target groups (e.g. pregnant women, under-18s, ethnic minorities, lower incomes)
- Detailed breakdown of clients by different demographics (e.g. age, gender, ethnicity etc)
- Outcomes (e.g. numbers of clients setting quit date, quitting, CO validated, lost to follow-up)
- Budgetary/Funding information
- Staffing/Resource information
- Results of users' evaluations of the service

Again there are data protection issues that would need to be addressed in the development of such a system (for example, only anonymised data should be used when writing reports to ensure that individual client's are not identified).

#### 3.5 *A feature for identifying clients for follow-up*

This feature would decrease the amount of time that smoking cessation professionals presently spend following-up clients. It would

be useful if it was linked to a facility to automatically generate letters for clients for the purposes of follow-up. This feature might be best placed as an optional aspect of the data management system, given that some services are better able to track clients than others (i.e. those with smaller numbers of clients). Again, as such services expand, we envisage that this feature would increase efficiency. Our consultations suggest that this facility would already be very beneficial to larger smoking cessation services.

### 3.6 *A feature for identifying clients that are re-referrals to a service*

Consultation findings suggest that re-referrals linkage would be a helpful feature of a data management system. It would be especially useful for services to know the time frame for referrals that were flagged up, i.e. how long ago they last had contact with the service and how many times they had attempted to quit previously using the support of the service. It would also be beneficial to have a system that gave further details about the client's history, such as pertinent medical history and treatments tried before.

This information would again save time on the part of practitioners, who often have to find out this information manually from their files. At present practitioners often identify re-referrals from memory, although the practicalities of being able to remember previous clients decreases as services expand. Practice nurses and other health professionals who conduct smoking cessation work would also find this feature useful in terms of the time it would save them on a day-to-day basis. Furthermore, if professionals know the referral time-frame before seeing a client, they could also tailor their advice more effectively to the individual's specific needs and situation.

### 3.7 *A feature for flagging up clients with a tendency to miss appointments*

This feature would decrease the amount of time that smoking cessation professionals currently invest in following-up clients, as they would be able to identify clients that do not attend sessions more readily, and at an earlier stage than is currently possible. In such cases, where there may have been a minor relapse, contacting the client early on could encourage them back into the service in good time, preventing an unsuccessful quit attempt and thus positively influencing cessation rates. It would also be especially valuable in informing and reviewing training and support systems.

This feature could also assist practitioners in finding out *why* people do not come to appointments. Currently there is little research evidence to suggest why people stop attending sessions, and yet an enhanced understanding of the factors that combine to influence non-attendance would be a valuable step in terms of effectively informing further

development of services. Indeed, we would recommend that the Scottish Executive commissions nationwide research into the reasons why clients do not attend appointments with smoking cessation services.

It would also be possible for the system to incorporate an automated letter that services could send to clients who do not attend a session, reminding them that the service is still there should they wish to get in contact. Again this would reduce the amount of time spend on administration of this kind. This feature might be best placed as an optional aspect of the data management system, given that some services are better able to track clients than others (i.e. those with smaller numbers of clients). Again, as such services expand, we envisage that this feature would increase efficiency. Our consultations suggest that this facility would already be very beneficial to larger smoking cessation services.

### 3.8 *A feature for identifying priority cases*

Where applicable, we recommend that services have a system in place for identifying priority cases that are referred to them, to enable fast-tracking through the system. This is especially relevant where services have a larger maximum capacity for clients. As priority cases are likely to differ according to locality and nature of the service provided, we would recommend that such a system be implemented locally, rather than at national level. However, it should be noted that while the focus on White Paper priority groups<sup>2</sup> is important, it is imperative that *any* smoker wanting to stop should be able to receive support.

### 3.9 *Best practice guidelines for data storage and data protection*

Our consultations revealed that some service providers are unsure about data protection guidelines and how they relate to their work. In particular, smoking cessation services should be aware of issues surrounding client consent (particularly if information is going to be shared with anyone), procedures for securely storing data, ensuring that data should not be kept for longer than is necessary and ascertaining that only anonymised data is analysed and reported.

A short set of data protection best practice guidelines will be included in the protocol for use of the minimum dataset (see Appendix 1). These will outline the eight data protection principles<sup>iv</sup> and offer guidance on how to ensure that these are followed.

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<sup>iv</sup> The data protection principles state that personal data must be: fairly and lawfully collected and processed; processed for limited purposes; adequate, relevant and not excessive; accurate; not kept for longer than is necessary; processed in accordance with individual's rights; secure; not transferred to other countries without adequate permission. For more information see: [www.dataprotection.gov.uk/principi.htm](http://www.dataprotection.gov.uk/principi.htm)

### 3.10 *Developing a data management system*

The proposed data management system is intended to make life easier for service providers and use of the extra features would be optional. For optimal performance the proposed system would need to work in harmony with commonly used computer packages, and with existing clinical electronic systems which are integral parts of NHS Scotland's information technology system. It would also have to be adaptable to the small number of smoking cessation services that operate outside of the health service (e.g. within Local Councils). Additional issues, such as the security of storing and transferring data, and compatibility with future software updates, would also need to be taken into account in the design of such a system.

A bespoke data management system would have to be maintained and advanced on a long-term basis, and training and support provided for users. Therefore it might be advantageous if an external company was commissioned to develop such a system, to provide training materials (e.g. handbooks, demonstrations), to be at hand to solve problems that arise and be able to develop the system in light of future requirements. PATH is in the process of consulting with IT experts about the practicalities and costs of developing of such a system.

As part of this process we may also consult with GPs and other health professionals who refer clients onto specialist services, to find out more about their views on provision of smoking cessation advice and how they would best benefit from a computer based system for smoking cessation services (see 3.3 and 5.6).

## **4. Recommendations for minimum standards: staff and resources**

4.1 Our consultations suggest that many services feel understaffed and under-resourced. Additional resources are necessary to meet current demand and to further develop and expand services. Indeed, additional funding is essential to implement the recommendations on data collection outlined in this report. We have devised the following recommendations for minimum standards of service provision, focusing particularly on staffing roles and requirements.

### 4.2 *Service Provision*

Each NHS Health Board should provide and fund one or more Smoking Cessation Service, depending on the population size and geographic distribution of its smoking population. One service should be able to

serve an adult population of about 250,000<sup>v</sup>. This should be taken as a guide only and service provision adapted to a level appropriate for local population size and demand. Therefore, we acknowledge that some areas will certainly require more than one dedicated service. Smoking cessation services should be funded on a *permanent basis* to ensure that they are helping smokers to the best of their potential (see section 4.9 for more information).

#### 4.3 *Staffing requirements*

Dedicated staff are needed to manage the services. Each specialist smoking cessation service should be led by a full-time equivalent smoking cessation co-ordinator who has overall responsibility for the service. In addition, each specialist service needs additional staff to work directly with quitters, to evaluate all aspects of the service and to provide administrative support. It is estimated that two or three full-time equivalent staff, in addition to the coordinator, are required for an adult population of around 130,000<sup>iv</sup>. However, we recognise that staffing levels may be greater or less depending on local population size, distribution and demand.

We have identified 4 broad functional roles to be fulfilled by professionals working in dedicated smoking cessation services: co-ordinators, specialists, 'officers' and administrators. While the following recommendations assume that these roles would be separate posts, we acknowledge the flexibility for these remits to overlap and be shared if required (for example in smaller Boards), to ensure that smoking cessation teams work in the most efficient manner. We also appreciate that these recommendations may need to be reviewed following the introduction of annual negotiated targets for each NHS Board for the number of individuals who give up smoking.<sup>14</sup>

#### 4.4 *Smoking Cessation Co-ordinators*

We recommend that Health Boards employ at least one full-time equivalent smoking cessation co-ordinator who has overall responsibility for the management, running and evaluation of all aspects of the service. The main tasks of smoking cessation co-ordination include overseeing the service, implementing service strategies, publicising the service, organising training, ensuring that the service adapts to changing needs, and acting as a key point of contact with other services, professionals and organisations. Where possible co-ordinators should be encouraged to maintain their clinical skills and

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<sup>v</sup> This level was advocated in the (draft) Revised Smoking Cessation Guidelines for Scotland. Please refer to the finalised Guidelines (due for publication in late 2003) for more details on staffing recommendations.

retain some contact with clients so that they remain able to offer authoritative advice and support to the team.

Where there is more than one smoking cessation service in a Health Board area, one co-ordinator should oversee the delivery of the services across that area and act as a link with other staff and activities at the Health Board level. The advantage of having a full-time co-ordinator with such an overseeing role is that more time can be spent on developing services, and more detailed consideration can be given to each stage of this process, in order to ensure long-term effectiveness of service provision.

#### 4.5 *Smoking Cessation Specialists*

The term smoking cessation specialist is used to refer to a dedicated smoking cessation practitioner who supports smokers through the process of a quit attempt. Smoking cessation specialists are individuals specially trained to offer behavioural and pharmacological support, who have dedicated time set aside for the purpose rather than attempting to fit the job with other duties. These staff provide treatment to smokers in groups or individually, and may also support a larger team of community smoking cessation practitioners operating in primary care. This role might be referred to elsewhere as smoking cessation advisors, counsellors or practitioners.

Given the importance of front-line staff, each service should have at least one full-time equivalent smoking cessation specialist, although the number will of course depend on the size and scope of the service.

#### 4.6 *Smoking Cessation Officers*

Our consultations suggest that services could benefit in a number of ways from the creation of a new post within smoking cessation teams, what we have termed a 'smoking cessation officer'. The smoking cessation officer remit could involve conducting 3-month and 12-month follow-ups. (It is envisaged that 1-month follow-ups would still be carried out by the practitioner running the group, as these tend to coincide with the final treatment session). This would free up time that practitioners and/or co-ordinators currently spend on following-up clients, allowing specialists to make more efficient use of their time working with clients in groups and one-to-one sessions, and leaving co-ordinators with more time to spend on service development and strategy implementation.

The role could also involve other aspects of service delivery and administration, such as data entry, thus increasing support resources where possible. Additional smoking cessation officer roles would be decided at service level to acknowledge the diversity of service

provision across Scotland and differing priorities that services have in terms of client groups. Service co-ordinators or other pertinent managers would have the flexibility to decide which additional remits would be most beneficial for the cessation officer to undertake, to ensure that the team as a whole works in the most efficient manner possible.

Suitable training would need to be provided for the new smoking cessation officers. Although follow-ups are conducted for information purposes, they can also be regarded as clinical interventions with the clients. For example, a relapsed smoker may wish to talk about their quit attempt and might want advice on future quit attempts. Officers would therefore need background training into smoking cessation issues and counselling skills to interact effectively with clients.

The number of smoking cessation officers required and their working hours would depend on the level of provision offered by the Health Board area. Further consultation with co-ordinators will be required to establish how much work there would be for an officer to do in each area, and the type of contract required. Additional revenue would need to be identified by the Scottish Executive and Health Boards in order to fund this new position.

#### 4.7 *Administrators*

We recommend that services employ a full-time administration worker, although again we acknowledge that smaller services might have different requirements. The benefits of having a full-time worker are substantial, as co-ordinators and practitioners often become involved in additional administration tasks that leave them insufficient time to focus on delivering services, or improving those services longer term.

#### 4.8 *Wider Smoking Cessation Support*

In addition to dedicated core staff working in specialist smoking cessation services, we acknowledge that individual support for smokers is also undertaken on a sessional basis by trained health professionals working in the community, such as practice nurses and pharmacists. This approach is essential to enable the services to respond to changes in demand (e.g. at New Year, after 'No Smoking Day', in reaction to promotional campaigns and following HM Treasury budget announcements on tobacco taxation), without making smokers wait for treatment. We also acknowledge that other health professionals, including GPs, have a role in providing brief opportunistic advice to smokers that may trigger a quit attempt. These approaches should continue to operate and be funded alongside specialist smoking cessation services.

#### 4.9 *Salaries and Contracts*

The NHS's 'Agenda for Change' pay modernisation scheme, which will be implemented across the UK by early 2005, will standardise the pay of smoking cessation workers within the NHS. We recommend that smoking cessation staff (co-ordinators, officers, specialists and administrators) working in non-NHS settings have salary scales in line with their NHS counterparts.

We strongly recommend that smoking cessation services are funded on a permanent basis and that staff working in smoking cessation teams are employed with permanent contracts. This is essential to avoid problems such as job insecurity, high staff turnover, loss of expertise and recruitment difficulties which may arise out of short-term funding. Specialist services need staff with appropriate skills and experience, which are not as readily developed and sustained within temporary situations.

#### 4.10 *Training and Continued Professional Development*

The skills of all staff working in smoking cessation services should be maintained and developed through a programme of training and continued professional development. This will ensure that smoking cessation professionals keep their skills and knowledge, and awareness of the latest research and developments in smoking cessation work, up-to-date. Services will benefit from updated and enhanced practices at both local and national level. Dedicated training will also enhance the standing of smoking cessation as a specialist profession in its own right.

Our consultations also suggest that many smoking cessation professionals would welcome assistance in aspects of business organisation and administration, such as managing budgets or making bids for funding. Training on the use of the proposed minimum dataset and data management system will also have to be provided.

We recommend that all smoking cessation staff undertake update training on a regular basis, and at least once a year. A number of protected in-service days should be set aside annually for continued professional development. Allowances for staff development should be built into services' budgets, with allocated funding for locum cover. With secured time to undertake training, staff will benefit from being able to plan in advance to attend such events.

We acknowledge that those in remote locations (particularly in Highland and Island Boards) have specific needs surrounding access to training. To maximise the accessibility of smoking cessation training, training should be delivered in a range of geographic locations across

Scotland. Investigations should also be made into setting up on-line and/or distance learning for smoking cessation training.

It should be noted that PATH's Training and Development Officers are developing national standards for the content and delivery of training for smoking cessation support. The forthcoming training standards and training strategy documents will provide further details on issues related to training. These will be available on request.

#### 4.11 *Other Resources*

A well-resourced, modern office is indispensable for the smooth running of smoking cessation services. We advise that all services are equipped with a computer (with email and internet facilities), telephone and answering service. An up-to-date computer is vital if the proposed nationwide data management system is to work to its full potential. This will facilitate effective two-way communication between smoking cessation staff, their clients and other health professionals, and will assist in data management tasks. This should increase efficiency and free up staff members' time to do tasks specific to their own remit.

### **5. Enhancing partnership work**

5.1 Our consultations suggest that to improve service delivery a more integrated approach to smoking cessation provision is necessary. Strategies to improve relationships and increase communication with others working in the field of smoking cessation and tobacco control, and with other health professionals involved in smoking cessation, are desirable. Increased partnership work should enhance service provision, both generally and in relation to work with specific groups such as pregnant women and adults with mental health difficulties.

#### 5.2 *Enhanced networks for information and support*

Smoking cessation professionals would profit from enhanced support and information sharing with others working in the field. Our consultations suggest that practitioners would benefit from the establishment of a network to facilitate the exchange of information relating to smoking cessation work (e.g. general progress reports on cessation work being done in different areas, innovative projects, best practice guidelines, literature reviews, guidance for work related to key areas reflecting the White Paper priorities, a regularly updated list of funding sources).

Such a network could take the form of either an e-mail discussion group, or a forum that meets occasionally to allow practitioners to exchange ideas and be kept informed of each other's work. This would

tie into the existing forum for smoking cessation co-ordinators which operates through the Scottish Tobacco Control Alliance (STCA). Indeed, we acknowledge that a great deal of information sharing already takes place through forums such as the STCA and the GLOBALink<sup>vi</sup> tobacco control website. These networks are highly valued and should be encouraged to develop and work to meet the changing needs of smoking cessation professionals.

### 5.3 *Enhancing partnership work with other health professionals*

Effective communication between smoking cessation staff and other health professionals, particularly those who have a role to play in offering brief opportunistic advice or referring clients on for specialist support, is important for the smooth operation of services. It is essential that all health professionals are aware of the health risks associated with tobacco and what can be done to help smokers to stop. They should have adequate information about smoking cessation services that operate in their local area and know when it is appropriate to refer clients on.

### 5.4 *Improved smoking cessation training for all health professionals*

We advise that tobacco education, smoking cessation and health behaviour change should be part of the core curriculum of the basic training of all health professionals, including doctors, nurses, midwives, dental staff and pharmacists. Providing information in the pre-qualification stage should lead to better standards in future. Protected time for update smoking cessation training post-qualification is also necessary to build upon skills and confidence to provide brief interventions, and to ensure that this area is not overlooked in the busy workloads of health professionals. Further discussion of smoking cessation training is covered in PATH's forthcoming training standards and training strategy documents, copies of which will be available on request.

### 5.5 *Better guidance regarding referrals*

Our consultations suggest that presently smoking cessation services receive many inappropriate referrals, particularly from GPs. This can lead to large numbers of clients who do not attend sessions and lower success rates. Doctors need clearer guidance to help them identify patients who are truly motivated to stop smoking before referring them on to services. The forthcoming revised Smoking Cessation Guidelines for Scotland contains a 'desktop' flowchart for brief advice to smokers

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<sup>vi</sup> [www.globalink.org](http://www.globalink.org)

that could be issued to all GP practices. This could also be incorporated into a computerised referral system. The issue of inappropriate referrals is a complex one and for the benefit of services we recommend that the Scottish Executive commissions further research into this matter.

#### 5.6 *Further consultation with health professionals*

To ensure that these recommendations are beneficial for all professionals involved in providing smoking cessation advice at whatever level, we hope to consult with health professionals, particularly GPs, to identify attitudes and needs related to the provision of smoking cessation advice. We would like to look at their experiences of providing brief interventions and what could be done to make the referrals process easier and more effective for them. In particular we would like to find out their thoughts on a computerised referrals system and find out if there are any other features of a computerised system they would benefit from (see points 3.3 and 3.10).

Representatives of bodies such as the British Medical Association and NHS Education for Scotland (and practitioners such as midwives) have already been closely involved in the various developments being led by PATH. We will continue to develop such relationships as part of our support measures for more effective and efficient smoking cessation work.

## **Appendix 1 (Draft) Protocol for use of the minimum dataset**

Please note that the minimum dataset and best practice guidelines for data collection given in this document are DRAFT versions. These were superseded in August 2004 by the document '*The Minimum Dataset for Scottish Smoking Cessation Services: Final Version and Guidelines for Use*'.

This updated document is available on the ASH Scotland website:  
<http://www.ashscotland.org.uk/inequalities/minimumdataset.pdf>

It is important that all smoking cessation services use standard definitions of key terms and procedures to ensure consistency and validity of monitoring and evaluation information. Those involved in the monitoring and evaluation of services should *read and understand* the following protocol before using the minimum dataset. This protocol offers definitions of items in the minimum dataset and clarifies procedures for data collection. It also offers advice on data storage and transfer, and on seeking client consent, which are vital to ensure that all data is gathered and used in accordance with Data Protection and Patient Confidentiality guidelines (see Section E for more information).

NB: This draft version of the protocol is for illustrative purposes only and may require further modification once the dataset has been piloted and once the data management package has been developed.

### **A. The minimum dataset**

The minimum dataset for each individual client consists of the core, information necessary for national statistical monitoring of smoking cessation services. It is anonymised data that will be sent to a central research team for research and audit purposes:

#### ***Section A - Client Demographics***

1. Health Board Area
2. Local Health Care Co-operative (if applicable)
3. Unique client identifying number
4. Full postcode
5. Date of birth
6. Gender
7. If female - pregnant at quit date?
8. Ethnic origin
9. Entitlement to free prescriptions
10. Entitlement to income support

#### ***Section B – Tobacco Use and Quit Attempt***

11. Number of cigarettes smoked per day?
12. How soon after waking does client usually smoke their first cigarette?
13. How easy or difficult would client find it to go without smoking for a whole day?

14. Number of previous quit attempts within the past year?
15. Set quit date
16. Has client received NRT and /or Bupropion (Zyban)?
17. Type of intervention used

**Section C – Outcomes of Intervention**

18. Self reported quit at 1 month?
19. Carbon monoxide validated quit at 1 month?
- 20-21. Self reported quit at 3 months?
- 22-23. Self reported quit at 12 months?

Further details on each of the minimum dataset items, including the reasons for collecting this information and how to record each item, are given below.

NB: It is important to obtain client’s consent to collect, store and use their data. Please refer to Section E on Patient Confidentiality and Data Protection for further information.

**1. Health Board Area**

This is used to measure uptake by area. There are 15 options for Health Board area:

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

**2. LHCC**

There are various options for LHCC (including not applicable) depending on the Health Board area selected.

**3. Unique client identifying number**

A unique reference number should be given to each client as an anonymised method for linking data and to enable resolution of any queries arising after submission of anonymised data.

NB: The system for allocating reference numbers has yet to be decided, but will be selected to ensure consistency and avoid duplication.

**4. Full postcode**

Full postcode (e.g. EH2 2HB) is recorded as a proxy for socio-economic status. Full postcodes can be mapped onto further local information to

provide a deprivation category (depcat) score, which can then be used to measure service uptake by adults on lower incomes, one of the identified priority groups. Full postcode allows for a more sophisticated analysis than partial postcode.

## **5. Date of Birth**

Clients' date of birth (date/month/year - e.g. 01/01/1960) is required to measure uptake by different age groups. Young people in particular are identified priority groups. Clients' age at quit date can be calculated using their date of birth and quit date.

## **6. Gender**

This item is collected to measure uptake of services by men and women.

## **7. If female - pregnant at quit date?**

It should be recorded if women using smoking cessation services are known to be pregnant. This is to measure uptake by pregnant women – an identified priority group.

## **8. Ethnicity**

This is used to measure uptake by different ethnic groups. The categories to be used for ethnicity are based on those used in the 2001 National Census in Scotland, which are as follows:

- White (Scottish; Other British; Irish; Any other White Background)
- Any Mixed Background (White and Black Caribbean; White and Black African; White and Asian; Any other Mixed Background)
- Asian/Asian Scottish or Asian British (Indian, Pakistani, Bangladeshi, Chinese, Any other Asian background)
- Black/Black Scottish or Black British (Caribbean, African, Any other Black group)
- Other Ethnic Background

## **9. Entitlement to free prescriptions**

This is an additional measure of socio-economic status, to determine uptake of services by people on lower incomes (a priority group). This is valuable because there are limits to the use of postcode as proxy for

socio-economic status, especially in rural or island areas. Furthermore, from a cost perspective, it is useful to find out how many clients using smoking cessation services are entitled to free prescriptions for NRT and Bupropion (Zyban).

**10. Entitlement to Income Support**

This is an additional measure of socio-economic status, to determine uptake of services by people on lower incomes (a priority group). This is valuable because there are limits to the use of postcode as proxy for socio-economic status, especially in rural or island areas. There are also limits to entitlement to free prescriptions as a measure of income, as some people who qualify for free prescriptions are not necessary on low incomes (e.g. people with certain long-term medical conditions or disabilities, people over-60, pregnant women, children).

**11. Approximately how many cigarettes does the client smoke per day (before quit attempt)?**

This question is asked to gauge clients' tobacco use and level of addiction, and to provide further context to the quit attempt and outcomes. The minimum dataset will offer four options:

- 10 or less
- 11-20
- 21-30
- More than 30

**12. How soon after waking do you usually smoke your first cigarette?**

This question is used to gauge client's level of dependence on cigarettes, to provide context to the quit attempt and outcomes. Four options will be offered:

- Under 5 minutes
- Between 5-15 minutes
- Between 30 minutes and 1 hour
- Longer than 1 hour

**13. How easy or difficult would you find it to go without a cigarette for a whole day?**

Another question to assess a client's level of dependence on cigarettes. Four options are offered:

Very easy  
Fairly easy  
Fairly difficult  
Very difficult

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

This is asked to measure the number of recent unsuccessful quit attempts and to provide further context to the quit attempt and outcomes.

The minimum dataset will offer four options:

No quit attempts  
Once  
2 or 3 times  
4 or more times

**15. Quit date**

A quit date indicates that a client is serious about trying to give up smoking and gives a definite point from which to measure follow-ups. Only clients who actually set a quit date (measured as date/month/year - e.g. 01/01/2003) are to be included in the national monitoring. Those who access smoking cessation services and/or receive counselling but do not go on to set a quit date are beyond the scope of central national monitoring. Information on clients who do not set a quit date may however be collected for local planning purposes and may be included in quarterly/annual commentary reports.

For national monitoring purposes, clients who set repeated quit dates should only be included in the monitoring once per quarter, with the outcome of the latest quit attempt.

**16. Has client received NRT and/or Bupropion (Zyban)?**

Information on clients who set a quit date and receive NRT and/or Bupropion (Zyban) is included in the minimum dataset. This information will be used measure the number of clients using this treatment and to analyse how this might affect outcomes. 'Received' includes all methods by which a client might obtain the relevant pharmaceutical aid(s) (e.g. through prescription, supply free of charge or purchase). Information is sought about clients who received these aids, so it is not necessary to confirm whether the client actually used them. Clients who began a course of treatment but discontinued it for whatever reason (for example, due to side effects) should be included. The possible answers for this question are as follows:

NRT only  
Bupropion (Zyban) only  
Both NRT and Bupropion (Zyban)  
None

## 17. Type of intervention

This information is collected to measure which interventions are being used by services and to compare outcomes. The options for this item are as follows:

Group support  
One-to-One sessions  
Group and one-to-one sessions  
Pharmacy scheme  
Buddy Scheme  
Other (please specify)

NB. There is also the possibility of creating a unique practitioner identifier which is linked to a database containing information about the kind of service provided. This requires further investigation.

## 18. Self reported quit at 1 month?

This information is required to assess the short-term success of cessation interventions. The client should be counted as having successfully quit smoking if they report that they have *not smoked (not even a puff) in the last two weeks*. This allows a 'grace period' in recognition of the fact that some smokers initially struggle but then manage to stop. It also brings procedures for measuring quit rates in Scotland broadly in line with the rest of the UK. To ensure consistency the following question and answers should be used:

Have you smoked at all (even a puff) in the last two weeks?

No  
Yes  
Not Known (e.g. client lost to follow-up, did not consent to follow-up)

All clients should be followed-up 1 month (approximately 4 weeks) after their quit date. If they cannot be contacted at this time further attempts should be made within a two-week period. The total time within which follow-up must be completed is 6 weeks after the quit date. If it has not been possible to contact a client within 6 weeks of their quit date, the individual should be counted as 'not known - lost to follow-up'. This cut-off point should help to promote meaningful and

consistent data, and puts Scotland in line with procedures already instigated in England.

At the 1-month follow-up it is preferable for the professional who provided the intervention to see the client *in person*. The smoking cessation worker and client will have established a rapport in the preceding weeks which should encourage honesty from the client regarding their quit attempt. Additionally, seeing the client in person enables a carbon monoxide monitor reading to be taken to validate the self-reported smoking status (see point 19 below). If, in exceptional circumstances, clients cannot be seen in person, they should be contacted by telephone for follow-up.

Immediately after the 1-month follow-up has been completed the client data should be forwarded to the local smoking cessation co-ordinator. (NB. With the new data management system this should be done electronically. In the piloting stage, before the computerised system has been developed, returns may be paper-based). A copy of the data should be kept for local records, as services will need to access the data for further follow-ups (3-month and 12-month).

NB. The minimum dataset only asks for information about quit rates and does not include information on clients who change their tobacco use in some other way (e.g. those who smoke less, those who no longer smoke indoors or in front of children or other non-smokers). These are outside the scope of national monitoring, but services may wish to collect such information for use at the local level (see point B).

#### **19. Carbon monoxide validated quit at 1 month?**

Carbon monoxide readings should be taken from all clients at the 1-month follow-up (unless, under exceptional circumstances, the follow-up was not conducted in person). It is recognised that carbon monoxide breath monitors are an important motivational tool for clients undergoing cessation treatment. They are also useful for validating that a person is a non-smoker and provide an additional, reliable measurement of short-term quit rates. The minimum dataset includes a question about whether CO validation was attempted and the outcome:

Does carbon monoxide monitor reading confirm quit?

No

Yes

CO reading not taken (e.g. client lost to follow-up, did not consent to follow-up, followed-up by phone/post)

Service providers may use whichever brand of CO monitor they prefer. They should ensure regular calibration and maintenance of their

monitors, in accordance with manufacturers instructions, to provide accurate and consistent readings. Clinical research guidelines suggest that a reading of less than 10ppm indicates that the user has not smoked in the last day, although once again the instructions should be referred to before noting if the reading confirms the client's self-reported smoking status.

## **20-21. Self reported quit at 3 months?**

In addition to the initial 1-month follow-up, all consenting clients should be followed-up at 3 months after their quit date. This provides a longer-term assessment of success rates for national monitoring. Furthermore, contacting clients at 3 months might encourage quitters to try again if a relapse has occurred, and gives the opportunity to check that a client's contact details are correct. Two questions are asked at the 3-month follow-up:

Have you smoked at all (even a puff) since we asked you about your smoking at the 1-month follow-up?

No

Yes, between 1 and 5 cigarettes in total

Yes, 5 cigarettes or more

Not Known (e.g. client lost to follow-up, did not consent to follow-up)

Have you smoked at all (even a puff) in the last two weeks?

No

Yes

Not known (e.g. client lost to follow-up, did not consent to follow-up)

This offers a useful indication of the number of clients who self-report as being non-smokers at this point in time, and people who have essentially been abstinent but might have had minor lapses at some point. Validation by carbon monoxide breath monitor is not essential for the minimum dataset at the 3-month follow-up.

All clients should successfully quit smoking at the 1-month follow-up should be contacted again 3 months after their quit date. Clients may be contacted either by telephone or letter. We suggest trying 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 'not known - lost to follow-up'.

NB. Permission to contact clients for follow-ups should be obtained early in the cessation interventions, for example when the client sets their quit date. The clients should be notified that the person seeking consent might not be the one who conducts the later follow-ups. See points D and E for more information.

## **22-23. Self reported quit at 12 months?**

All clients should successfully quit smoking at the 1-month follow-up should be contacted again 12 months after their quit date, to give an indication of the longer-term success of a cessation intervention. Attempts should be made to follow-up clients at this point even the 3-month follow-up was unsuccessful (e.g. if they could not be contacted at the 3-month follow-up or if they had resumed smoking then). The procedures for assessing self-reported quit at 12 months is the same as at 3 months:

Have you smoked at all (even a puff) since we asked you about your smoking at the 1-month follow-up?

No

Yes, between 1 and 5 cigarettes in total

Yes, 5 cigarettes or more

Not known (e.g. client lost to follow-up, did not consent to follow-up)

Have you smoked at all (even a puff) in the last two weeks?

No

Yes

Not Known (e.g. client lost to follow-up, did not consent to follow-up)

Clients may be contacted either by telephone or letter. Any client who could not be contacted after multiple attempts should be counted as 'not known - lost to follow-up'.

These two questions at the 3-month and 12-month follow-ups provide two different measures of a successful quit attempt. The first question offers a measurement of prolonged abstinence – smoking rates over a longer period of time. This counts as successes people who are essentially abstinent but might have had minor lapses at some point. The second question gives a measurement of point prevalence smoking rates – in other words smoking rates during a 2-week window of time. This offers a useful indication of the number of clients who are abstinent at a given point in time. It will be interesting to compare the differences between these two measurements in terms of numbers of successful quitters.

## **B. Additional Local Data**

The above information is the minimum necessary for national monitoring of smoking cessation services. However, further information may also be useful to guide interventions and to assist in *local* service planning and monitoring, either at the level of the individual service, LHCC or Health Board.

Services will need to collect core information, such as the client's name, address and telephone number, to identify clients for treatment and follow-ups. Further data that is important at service level includes the client's medical history and GP. We also recommend finding out details about each client's tobacco use and motivation to stop at the beginning of their contact with the service. Likewise, we encourage services to find out additional information at follow-ups about the outcomes of interventions (e.g. changes in the client's knowledge, attitude and behaviours towards smoking) and about client's opinions of the service (e.g. evaluations of different aspects of the service). This kind of information offers a more general context to service achievements. The above sorts of information are *useful* for the service, but are *not essential* for national, anonymised statistical monitoring.

## **C. Data Gathering, Storage and Transfer**

The data required for the minimum dataset and any additional information will be collected from clients during the course of their involvement with the service (for example from an initial client registration form) and from follow-ups (either in person, by telephone or by mail). It may be easier to collect information initially on paper and to transfer it afterwards onto the computer database. We would advise that client information stored on computer is backed up and that original paper files are retained. All information must be stored securely at all times to ensure patient confidentiality.

Immediately after the 1-month follow-up has been completed the client data should be forwarded, either to the local smoking cessation co-ordinator, or directly to the central monitoring team (NB. The exact procedure has still to be decided, depending on the data management system adopted). A copy should be kept for local records, as services will need to access the data for later follow-ups.

## **D. Client Consent**

Please note that updated guidance on using client data was provided by PATH in July 2004 in the document '*Using Client Data: Data Protection, Client Confidentiality and Access to Information: Best Practice Guidelines for Scottish Smoking Cessation Services*'

This updated document is available on the ASH Scotland website:  
<http://www.ashscotland.org.uk/inequalities/clientdata.pdf>

To ensure compliance with the data protection regulations (see Section E), clients are entitled to be told the purpose(s) for which their data will be used and asked for their consent. If client consent is not obtained then the data cannot be said to have been 'fairly and lawfully processed' or 'processed in accordance with individuals' rights'. Data should only be used for the purposes for which permission was given, or for purposes compatible with these. So think ahead about what you want to use the information for. If you intend to share client data with anyone then the client's permission should be obtained beforehand.

Consent to contact clients for follow-ups at 1, 3 and 12 months should be sought, preferably near the beginning of their contact with the service (e.g. when they register with the service or at the time they set a quit date). The client should be made aware that the person contacting them for follow-up might be someone other than the worker who is seeking consent. Should a client refuse follow-up, either early on in contact with the service or later on at follow-up, records should be clearly noted to this effect.

We advise the following procedures for obtaining consent:

- Provide clear information on why information is being collected, and what it may be used for. This should be done verbally and with a clear, well-worded written information sheet. Offer clients the opportunity to ask questions, and ensure that the written information sheet includes suitable contact details, so they can get back in touch with any questions they may think of later on.
- Ask the client to sign and date their agreement to statement(s) relating to the information that will be gathered and how it will be used. It is preferable to ask separate questions relating to different aspects of consent (e.g. clients understanding of why data is being collected, agreement to have data stored and used for audit purposes, consent to be followed-up, permission to contact client's GP).
- Clients have the right to refuse and this should not affect their right to receive treatment. Any refusal should be noted.
- Include a distinct, clear data protection statement in the consent form.

An example showing appropriate content for an information sheet and a consent form are given at the end of the Appendix.

## **E. Client Confidentiality and Data Protection**

Please note that updated guidance on using client data was provided by PATH in July 2004 in the document *'Using Client Data: Data Protection, Client Confidentiality and Access to Information: Best Practice Guidelines for Scottish Smoking Cessation Services'*

This updated document is available on the ASH Scotland website:  
<http://www.ashscotland.org.uk/inequalities/clientdata.pdf>

All staff should be aware of their responsibilities for safeguarding confidentiality and preserving information security. All staff working with client data (e.g. gathering data, data entry, conducting follow-ups) should be adequately trained in data protection issues<sup>vii</sup>. Each NHS Trust or Board and Local Council should have a designated Data Protection Officer who can be contacted if you have any queries relating to Data Protection or confidentiality. You should refer to any existing data protection guidelines or policies offered by your NHS Trust, Board or Local Council.

The use of personal information is governed by a complex arrangement of laws and standards, including The Data Protection Act 1998. The Act came into force on 1 March 2000<sup>viii</sup> and covers most types of personal data, including that held on computer and in manual/paper-based filing systems. It enhances the rights of individuals who are the subject of personal data and expands the responsibilities of organisations which process personal data. (NB: The term 'processing' refers to anything done to personal data, including collection, storage, use, disclosure and destruction). Anyone processing personal data must comply with the eight data protection principles outlined below.

### ***The Eight Data Protection Principles***

Personal data must be:

- 1) Fairly and lawfully processed
- 2) Processed for limited purposes
- 3) Adequate, relevant and not excessive
- 4) Accurate
- 5) Not kept longer than is necessary
- 6) Processed in accordance with individuals' rights

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<sup>vii</sup> As a starting point, an NHS Scotland web-based training package on confidentiality and data protection can be downloaded from:

[www.show.scot.nhs.uk/elearning/availabletopublic/home.htm](http://www.show.scot.nhs.uk/elearning/availabletopublic/home.htm)

<sup>viii</sup> Further information on the Data Protection Act 1998 can be obtained from the following website: [www.dataprotection.gov.uk](http://www.dataprotection.gov.uk)

- 7) Kept secure (protected against unauthorised processing and accidental loss, destruction or damage)
- 8) Not transferred to other countries without adequate protection

It can be difficult to offer concrete definitions of what the data protection principles mean, as the language used is quite vague. What is important is to do the best you can to comply with legislation (see the best practice guidelines for data protection in smoking cessation services, below).

Further guidance on confidentiality and security requirements is outlined in the Caldicott Principles, which come from a 1997 report into patient confidentiality in the NHS in England and Wales<sup>ix</sup>. Although the Caldicott's remit did not extend to Scotland, a number of the Committee's recommendations are pertinent:

### ***The Caldicott Principles***

- 1) Justify the purpose for which the information is required
- 2) Do not use patient-identifiable information unless it is absolutely necessary
- 3) Use the minimum necessary patient-identifiable information
- 4) Access to patient-identifiable should be on a strict need-to-know basis
- 5) Everyone with access should be aware of their responsibilities
- 6) Understand and comply with the law

The following best practice guidelines are a good starting point, although we strongly encourage all staff to receive proper data protection training.

### ***Best Practice Guidelines for Data Protection in Smoking Cessation Services:***

- Obtain written consent from client to collect and use their data (see point D, above).
- Personal data should be securely held (e.g. on password protected computers, using computer firewalls, in locked filing cabinets).
- Ensure that only recognised people are dealing with your data. All staff working with client data should sign a written agreement ensuring confidentiality.
- Only anonymised summary data should be forwarded for national monitoring and evaluation.

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<sup>ix</sup> For more information on the Caldicott Committee's Report see:  
[www.doh.gov.uk/confiden/crep.htm](http://www.doh.gov.uk/confiden/crep.htm)

- Data may be held for as long as it is required - in other words as long as you can still justify why you might need it.
- If records are being kept for more than two years that they should be updated (records should be kept accurate) or their utility reviewed.
- Records should be disposed of carefully if there is no longer any reason for keeping them.
- Assure clients that you are trying to follow Data Protection legislation. It is good practice to display a public statement about your data protection arrangements in your premises and/or on your website, or provide information leaflets in the area where sessions are held.

The Scottish Executive have recently announced the development a work programme to promote best practice and improvement in the use of personal health information, whilst meeting the legal requirements of the Data Protection Act. As part of this programme, a new *Code of Practice for NHS Scotland Protecting Patient Confidentiality* has been produced. All NHS staff, students, volunteers and contractors have now received updated guidance on how to collect and protect patient information, including advice on issues including obtaining consent from clients, and patients' rights of access to their personal health records<sup>x</sup>.

Separate patient and staff information sheets on protection of personal health information have also been produced, and are being made available to all staff, and all clients who contact a service. Examples of both information sheets are available from the NHS Scotland Confidentiality and Data Protection website referenced on the previous page.

### ***Research ethics***

Client confidentiality and data protection are central issues if client data is being used for research purposes. Approval from a Research Ethics Committee (REC) is required before conducting research on NHS patients. In some cases it is also required for audit type research.

The purpose of a REC is to ensure that proposals for research studies comply with recognised ethical standards which protect the dignity, rights, safety and well-being of research participants. There are two types of REC – Local Research Ethics Committees (LRECs), which deal with research conducted on one 'site' only (i.e. the geographical area

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<sup>x</sup> For more information on the NHS Code of Practice on Protecting Patient Confidentiality see: [www.show.scot.nhs.uk/confidentiality/](http://www.show.scot.nhs.uk/confidentiality/)

covered by one NHS Board) and Multi-Centre Research Committees (MRECs) which deal with applications for research covering more than one research 'site' (i.e. in two or more NHS Board Areas).

The central research team that will be collating data from smoking cessation services from different health board areas will apply for MREC approval to carry out the national monitoring of smoking cessation services. However, individual services might also need to seek ethical approval if they wish to gather personal data for research and evaluation purposes. Contact the Central Office for Research Ethics Committees or the appropriate LREC administrator if you require further clarification on whether and whom you should apply for ethical review. For further information and contact details see:

[www.corec.org.uk/Scotland.htm](http://www.corec.org.uk/Scotland.htm)

## **Smoking Cessation Service Information Letter - Example**

-Clinic address and contact details-

Dear Service User,

As part of the Government's directive for the provision of smoking cessation services, this NHS Board is required to carry out an audit and evaluation of the services. We will count the numbers of people using smoking cessation services, the number of males and females and the age groups; the number of smokers who have stopped at the end of the session, those who have stopped 3 months and 12 months later, and numbers using Nicotine Replacement Therapy or Bupropion (Zyban). This information will be used to monitor the services performance and to help make decisions on future service provision.

We will need to hold a database with information about those attending smoking cessation services in order to do this. Any information used for evaluation purposes will be anonymous and will *not* include personal details (e.g. names, addresses, telephone numbers).

In order to help make decisions about the support you receive from the service and in order to contact you if necessary, your contact details will also be stored for use by service staff *only*. All data will be used in accordance to data protection legislation.

We would like your consent to hold your data on file and use it for the purposes outlined above. Please ask if you have any questions about how your data will be used. If you agree please sign the attached consent form.

Thank you.

### **Data confidentiality and security**

The information provided by you will be held in a secure environment in accordance with The Data Protection Act (1998). The information will only be used to assess the outcome of this project and no details will be passed on to any organisations who are not involved in the outcomes assessment.

## **Smoking Cessation Service Consent Form - Example**

**Please read and complete the following form. Please ask if you would like further explanation of any item and note that if you do not wish to give consent for any of the following you are still entitled to receive treatment.**

Please initial the box

1) I understand the information I have received about the smoking cessation service and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time.

2) I am willing for my details to be kept on a confidential database and for anonymised information to be used for the purposes of assessing outcomes of the service.

3) I agree to be contacted the end of the programme, and at 3 months and 12 months, to see how I am doing and give feedback on the service.

4) I am happy for my doctor to be told of my participation in this project, and that I am using NRT or Bupropion (Zyban).

Client's Name.....Signature.....

Date.....

### **Data confidentiality and security**

The information provided by you will be held in a secure environment in accordance with The Data Protection Act (1998). The information will only be used to assess the outcome of this project and no details will be passed on to any organisations who are not involved in the outcomes assessment.

## Glossary

**Brief opportunistic advice:** when a health (or other) professional brings up the issue of smoking with a client who smokes and attempts to trigger a quit attempt. Depending on the smokers' level of motivation, this may involve the provision of information on smoking and health, actual advice to quit or referral to a specialist cessation service. Also known as brief intervention.

**Client:** A generic word that can refer to a patient or service user

**Database:** a collection of data arranged for ease and speed of search and retrieval. This can take the form of a specialised piece of software.

**Minimum dataset:** the essential information to be collected for each client for national statistical monitoring of specialist smoking cessation services.

**Nationwide:** this report focuses on recommendations for Scottish Smoking Cessation Services and hence references to 'nationwide' refer to Scotland (not the UK).

**Priority groups:** groups of the population highlighted in the UK White Paper 'Smoking Kills' and the Scottish White Paper 'Towards a Healthier Scotland' as needing to be particularly targeted for smoking cessation work. These are young people, pregnant women and adults on a low income.

**Smoking Cessation Co-ordinator:** has overall responsibility for the management, running and evaluation of all aspects of specialist smoking cessation service(s) in a particular area. May also have contact with clients.

**Smoking Cessation Officer:** a proposed new post whose remit would involve conducting follow-ups, in addition to other aspects of service delivery and administration.

**Smoking Cessation Specialist:** Someone whose role is *exclusively* to provide specialist cessation support i.e. the work does not form part of a wider job remit. Also known as smoking cessation advisors or counsellors.

N.B. Other professionals offer specialist cessation support as *part* of their remits. For this reason, we have used the term **Smoking Cessation Practitioner** to refer generically to those who offer specialist cessation support, regardless of whether it is as part or all of their remit.

**Specialist cessation support:** Supporting a smoker through the process of a quit attempt. Can be carried out on a one-to-one or group basis and implies the provision of several behavioural support sessions both before and after a quit date, as well as possible pharmacological support. Specialist support can also be referred to as in-depth or intensive support, or as an in-depth or intensive intervention.

## References

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[http://www.ashscotland.org.uk/issues/pass\\_pass\\_smok.html](http://www.ashscotland.org.uk/issues/pass_pass_smok.html)
- <sup>5</sup> ASH Scotland and HEBS 1998 *A Smoking Cessation Policy for Scotland*. Edinburgh: The Health Education Board for Scotland
- <sup>6</sup> The Scottish Executive 2000 *Scottish Health Survey 1998 Volume 1*. Edinburgh: The Stationery Office (Chapter 8 on smoking)
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- <sup>10</sup> Hughes, J.R. et al. 2003 'Measures of abstinence in clinical trials: issues and recommendations', *Nicotine and Tobacco Research* Vol.5 pp13-25
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- <sup>13</sup> Gilpin, E.A. et al. 1997 'Duration of smoking abstinence and success in quitting', *Journal of the National Cancer Institute* Vol. 89(8) pp572-6
- <sup>14</sup> Scottish Executive 2003 *Improving Health in Scotland – The Challenge* Edinburgh: The Stationery Office