Alcohol
Deaths
Reviews
Practical Guidance for Alcohol and Drug Partnerships and Public Health Teams
Alcohol Focus Scotland (AFS) is the national charity working to prevent and reduce alcohol harm. We want to see fewer people have their health damaged or lives cut short due to alcohol, fewer children and families suffering as a result of other people’s drinking, and communities free from alcohol-related crime and violence.
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MINISTERIAL FOREWORD

We have been bold in our efforts to reduce alcohol harm, but it continues to take a significant toll on individuals, families and communities. Our most deprived communities suffer the most with people living in those communities over four times more likely to die as a consequence of alcohol consumption than those in our least deprived areas. Every death from alcohol consumption is a tragedy and each one is preventable.

Reviewing alcohol deaths within a local area will provide a better understanding of who is at risk from an alcohol death and will inform efforts better to support them. This gives us a further opportunity to reduce the number of lives lost in the future. That is why I am delighted to welcome the publication of this Alcohol Deaths Review Guidance.

This guidance gives a roadmap for Alcohol Drug Partnerships for the first time and will help NHS Public Health teams work together to conduct a review of alcohol deaths in their area. By distilling insight and learning from colleagues around the country who have experience of such reviews, the guidance provides practical advice to inform and support alcohol death prevention work across Scotland.

Local collaboration is crucial as it enables reviews to examine how people can best be supported across public and third sector recovery services. A constructive, open-minded approach which actively encourages participation in reviews is essential to increasing our understanding of how to better support people at risk of dying.

I encourage local organisations to make use of AFS’s project support and to join the Alcohol Deaths Researchers’ Network, which will provide a focal point for sharing learning on alcohol deaths prevention work as more reviews are undertaken and we expand our collective knowledge.

Preventing alcohol deaths and reducing health inequalities are at the heart of our Rights, Respect and Recovery strategy. This guidance, alongside other forthcoming work on alcohol deaths prevention, are part of our collective efforts to reduce alcohol deaths across Scotland.

Joe FitzPatrick
Minister for Public Health, Sport and Wellbeing
INTRODUCTION

This guidance is intended for use by Alcohol and Drug Partnerships (ADPs) and NHS Public Health teams concerned with alcohol deaths prevention. It is intended to be used as a reference manual for teams at any stage of planning alcohol death reviews, from initial consideration through to publication.

The guidance is the result of interviews with researchers and others associated with previous reviews of alcohol deaths across Scotland, drawing on their learning and experiences of undertaking reviews of deaths. These interviews were conducted during winter 2019 and spring 2020 and sought to find what had worked well, what could be learned from and what people would do differently if their reviews were repeated. We are grateful to all those who shared their experience and reflections to contribute to the project.

The sections of the guidance mirror the practical concerns and thinking to be done at all stages of review. Aware that local teams have varying priorities, interests and resources, we have developed this guidance to give a general overview of how alcohol death reviews can be carried out, leaving space for ADPs and NHS Public Health teams to develop their own reviews as they see fit.

This guidance forms one element of AFS’s support for teams concerned with alcohol deaths prevention, alongside the Alcohol Death Researchers’ Network and ongoing project support from the AFS team at meetings and remotely, as reviews are planned and undertaken.

For further information or support on alcohol deaths prevention please contact Simon Jones, 0141 572 6593 or simon.jones@alcohol-focus-scotland.org.uk

What are alcohol deaths reviews?

Reviews of alcohol deaths study information about a person’s life, and death, in order to evaluate what opportunities could be taken in future to prevent other people dying in similar ways.

Reviews of alcohol deaths involve gathering qualitative information to understand how alcohol played a role in a person’s life and eventual death. Reviews can draw on GP records, notes from acute treatment, third sector organisations and the recollections of families.

How can reviews help?

One of the major obstacles to preventing alcohol deaths in Scotland today is a lack of knowledge about how services might help people at risk of dying by alcohol, and the course of addiction through people’s lives before they die. Annual National Records of Scotland (NRS) statistical information is available, but little else is reported at the local or service level. The few reviews already undertaken show us how little we know about alcohol deaths.
Review process

**PHASE 1  Preparatory work**
- Consider resources available to the project: financial, personal and data
- Begin identifying people with the skills and values necessary for effective reviews
- Ensure participants from statutory and third sector organisations are able to participate
- Make contact with AFS so you can make use of wider support

**PHASE 2  Establishing the team**
- With a better idea of who can be on the review and data groups, approach potential members and hold an initial project team meeting
- Seek agreement on resourcing analyst(s) time at this stage, in partnership with NHS Public Health and ADP(s)

**PHASE 3  Planning the review**
- Compile local profile using NRS and Public Health Scotland (PHS) demographic data
- Identify question set and map data sources
- Obtain Caldicott approval for NHS records
- Consider whether a cohort study is needed
- Consider how the review will be used, identifying public and private data
- Decide at this stage if any specialist study will take place

**PHASE 4  Undertaking the research**
- Review group meetings should take place monthly to consider research from the data group
- Ensure there is a parallel structure to allow NHS staff to report on general findings from Caldicott data which cannot be shared with non-NHS staff
- Make use of the Alcohol Death Researchers’ Network meetings

**PHASE 5  Preparing and disseminating the findings**
- After file research is complete, work can begin on compiling public and non-public reports
- Make use of available communications expertise
- Begin drawing up action plan for systematic changes
Alcohol Deaths Reviews

Review Process

Alongside this guidance, AFS has established the Alcohol Deaths Researchers’ Network to facilitate communication, support and the sharing of information between people involved in reviews. Active and former researchers or analysts from across Scotland are welcome to join this network, which meets bi-monthly, and can be accessed by contacting Simon Jones at Alcohol Focus Scotland simon.jones@alcohol-focus-scotland.org.uk.

The process of conducting reviews provides a platform for examining the lives of people who have died, to generate information that can be used to inform service design and strategic approaches to prevent future deaths. By undertaking them, teams can focus their energy on understanding the complexity of problems that result in deaths by alcohol.

Those who have undertaken reviews already talk of them being uniquely helpful in framing an issue that can preoccupy our minds but seem too large to tackle. They give a full account of the challenges and barriers facing people with alcohol problems, and a starting point to alleviate them.

By generating useful data it becomes possible to understand how people interact with services; areas where practice could be innovated; new services which may help; and strategic approaches that can alleviate problems before they become fatal. It allows us also to evaluate the impact of changes made, and plan better for the future.

Values and aims of reviews

Alcohol death reviews offer an opportunity to undertake open-minded work with a view to improving the health of people across the country. Given the stark inequality in alcohol mortality - people in Scotland's most deprived communities are more than four times more likely to die than those in the most affluent communities1 - it also offers an opportunity to address this inequity. The people AFS have spoken with who are experienced in alcohol death reviews were unanimous in their enthusiasm for reviews, and believed they had made it possible to consider alcohol deaths in a way which was impossible before.

Having reliable data was identified as a crucial output, but so was building effective, collegial links across specialties and sectors. Though this guidance is largely technical, the values of collaboration, open-mindedness and curiosity were mentioned repeatedly by experienced reviewers as being crucial to the success of alcohol death reviews.

Every death by alcohol is a tragedy, and with AFS’s work being to assist local ADP and NHS Public Health teams in collaborating to reduce them, alcohol death reviews have a specific place in quality and service improvement. Reviews aim to evaluate and improve the coverage and provision of support for people at risk of dying by alcohol. They should achieve this through collaborative practice from the outset, ensuring that lessons can be learned and improvements implemented across the whole of the healthcare system, wherever a person might need support.

Alcohol-specific vs alcohol-related deaths

Often professional discussions use the general term “alcohol deaths,” but in fact there are two similar terms with different meanings, and the difference between them is critical for public health professionals.

Alcohol-specific deaths are ones which could not have occurred other than through alcohol use – these are reported by the NRS, usually in June. There are also annual statistics on the rate of alcohol-specific deaths published by the Office of National Statistics (ONS) every December and the MESAS monitoring reports in June address inequalities in relation to deaths.

Alcohol-related deaths is a broader definition. These include any death where alcohol is assessed as playing a role, not just being biologically caused by it. These can include alcohol-specific deaths plus other causes such as accidents, suicides, cancers and other physical conditions commonly linked to, but not directly caused by, alcohol use.

Alcohol-related conditions are far more numerous than alcohol-specific ones. Because of this there are usually practical decisions to be taken by researchers or analysts on which alcohol-related conditions their work will focus on. For a broad sense of the conditions which can be linked to alcohol misuse, ScotPHO’s 2018 Burden of Disease from Alcohol Consumption report is instructive. Having a clear sense of the conditions being examined will set the course for further developments in research, across the healthcare infrastructure and ultimately public health strategy. In most cases we would recommend first reviews examine alcohol-specific deaths only, but there is more guidance on p21-22, and AFS can be contacted for support in the planning stages of a review.

What is the national picture of alcohol-specific deaths in Scotland?

Scotland’s rate of alcohol-specific deaths is the highest in the UK. However, to date there has been relatively little study of how people who die by alcohol interact with the services and supports that are available.

We know that the number of alcohol-specific deaths (those caused solely by alcohol) rose from around 400 per year in 1990 to nearer 1,400 in 2000. In 2018, 1,136 people died of alcohol-specific causes across Scotland, following an upwards trend since 2012.

At the national level roughly twice as many men die from alcohol as do women, though at the local level this can fluctuate dramatically year-on-year. Without wider data it is hard to conclusively know why this is. We know also that, in line with other alcohol harms, alcohol deaths occurred over four times more frequently in the most deprived communities than the least in 2019.

How does alcohol cause deaths?

The following conditions are counted as alcohol-specific deaths in Scotland:

<table>
<thead>
<tr>
<th>ICD-10 Code</th>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>E24.4</td>
<td>Alcohol-induced pseudo-Cushing’s Syndrome</td>
</tr>
<tr>
<td>F10</td>
<td>Mental and behavioural disorders due to use of alcohol</td>
</tr>
<tr>
<td>G31.2</td>
<td>Degeneration of nervous system due to alcohol</td>
</tr>
<tr>
<td>G62.1</td>
<td>Alcoholic polyneuropathy</td>
</tr>
<tr>
<td>G72.1</td>
<td>Alcoholic myopathy</td>
</tr>
<tr>
<td>I42.6</td>
<td>Alcoholic cardiomyopathy</td>
</tr>
<tr>
<td>K29.2</td>
<td>Alcoholic gastritis</td>
</tr>
<tr>
<td>K70</td>
<td>Alcoholic liver disease</td>
</tr>
<tr>
<td>K85.2</td>
<td>Alcoholic induced acute pancreatitis</td>
</tr>
<tr>
<td>K86.0</td>
<td>Alcohol induced chronic pancreatitis</td>
</tr>
<tr>
<td>Q86.0</td>
<td>Foetal induced alcohol syndrome (dysmorphic)</td>
</tr>
<tr>
<td>R78.0</td>
<td>Excess blood alcohol levels</td>
</tr>
<tr>
<td>X45</td>
<td>Accidental poisoning by and exposure to alcohol</td>
</tr>
<tr>
<td>X65</td>
<td>Intentional self-poisoning by and exposure to alcohol</td>
</tr>
<tr>
<td>Y15</td>
<td>Poisoning by and exposure to alcohol, undetermined intent</td>
</tr>
</tbody>
</table>

Figure 1. Source: NRS Alcohol Deaths in Scotland 2018

Figure 2. Source: NRS Alcohol Deaths in Scotland 2018. Methodology Section
The graph below shows the proportion of alcohol-specific deaths by ICD-10 category in Scotland in 2018. Boxes for minor causes are left blank but all causes are shown in the full table below:

### Causes of Death, Scotland, 2018

<table>
<thead>
<tr>
<th>Category</th>
<th>Condition</th>
<th>Number of Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcoholic liver disease</td>
<td>Cirrhosis</td>
<td>259</td>
</tr>
<tr>
<td>Mental disorder</td>
<td>Dependence syndrome</td>
<td>228</td>
</tr>
<tr>
<td>Alcoholic liver disease</td>
<td>Unspecified ALD</td>
<td>200</td>
</tr>
<tr>
<td>Alcoholic liver disease</td>
<td>Hepatic failure</td>
<td>157</td>
</tr>
<tr>
<td>Alcoholic liver disease</td>
<td>Hepatitis</td>
<td>60</td>
</tr>
<tr>
<td>Alcoholic liver disease</td>
<td>Fatty liver</td>
<td>31</td>
</tr>
<tr>
<td>Other</td>
<td>Accidental poisoning</td>
<td>59</td>
</tr>
<tr>
<td>Mental disorder</td>
<td>Unspecified mental disorder</td>
<td>50</td>
</tr>
<tr>
<td>Alcoholic liver disease</td>
<td>Residual and late-onset psychotic disorder</td>
<td>25</td>
</tr>
<tr>
<td>Other</td>
<td>Acute pancreatitis</td>
<td>17</td>
</tr>
<tr>
<td>Mental disorder</td>
<td>Amnesic syndrome</td>
<td>13</td>
</tr>
<tr>
<td>Other</td>
<td>Chronic pancreatitis</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>Gastritis</td>
<td>4</td>
</tr>
<tr>
<td>Mental disorder</td>
<td>Harmful use</td>
<td>2</td>
</tr>
<tr>
<td>Mental disorder</td>
<td>Withdrawal state</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>Degeneration of nervous system</td>
<td>2</td>
</tr>
<tr>
<td>Alcoholic liver disease</td>
<td>Fibrosis and sclerosis</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>Intentional self-poisoning</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>Poisoning (undetermined intent)</td>
<td>1</td>
</tr>
</tbody>
</table>

Figure 3. Source: NRS Alcohol Deaths in Scotland 2018

Figure 4. Source: NRS Alcohol Deaths in Scotland 2018
These conditions typically arise from chronic exposure to alcohol in substantial amounts. Slightly more than half of alcohol-specific deaths were caused by alcoholic liver disease, with dependence syndrome another major cause.

Alcohol death reviews already undertaken in Scotland has found a routine level of alcohol consumption by those who died of around 180-230 units per week, or approximately 9 bottles of spirits. Those who died had typically developed a problematic relationship with alcohol by their late teens and had been in and out of contact with medical and other support services for years.

Alcoholic liver disease may take years to manifest through physical symptoms. In some cases people present with symptoms of decompensated liver disease, where the liver’s ability to regenerate is seriously affected, and their life expectancy may be a matter of months.

Alcohol deaths rarely trigger that legal process. The conditions which kill people tend to be chronic, developing over years, often with few or no physical symptoms until advanced damage has been done. While the role of drugs in deaths is assessed with toxicology study, for alcohol this is not the case. Assessing the role of alcohol in a death usually rests instead on determinations by the physician who completes the death certificate.

These differences in the nature of, and legal requirements relating to, alcohol and drug deaths have implications for the ways in which data are collected and reported for each. Alcohol’s status as a legal drug means very few alcohol-specific deaths trigger legal investigation after death.

The chronic nature of the conditions which cause deaths by alcohol mean that GP and other community-based records are of primary importance for understanding how a person lived and died.

These differences have to be kept in mind when reviewing alcohol deaths. Reviews of drug or alcohol deaths can yield similar qualitative data about a person’s life and their substance use, but there are structural differences in reporting which are important for researchers to keep in mind.

Where does data come from?

Whenever a person dies in Scotland, the death has to be registered. When this happens there are two documents issued – the first is a ‘short form’ death certificate, which can be taken away by families, and the other is the Medical Certificate of the Cause of Death form (MCCD).

The MCCD includes a primary cause of death and contributory causes, assessed by a trained physician. These causes correspond to ICD-10 codes, which are internationally-agreed, used to record illnesses and conditions throughout treatment and after death. These codes are used in the recording of alcohol deaths.

In cases of alcohol-specific deaths, ICD-10 codes recorded on the MCCD are more likely a matter of professional judgement than definitive post-mortem examination. This is due to the chronic nature of many conditions, alcohol’s legal status and other factors. Because of this, the role of alcohol in deaths across Scotland may be subject to some inconsistencies in reporting, for example in the absence of specialist testing or care. However, this should not affect reviews undertaken with this guidance. The aim is to get more information about the cases which are conclusively listed as alcohol-specific, or alcohol-related, within the current system.

The phases of reviewing

Previous reviews have varied widely in design and findings, but our research indicates a five phase model that can be of use to those planning future reviews. These are practical phases, which we believe can be undertaken in a 12-month period as part of a review, assuming effective planning and resources are available.

- **Phase 1: Preparatory work** – involves initial thinking and informal discussion with possible participants in the review, as detailed later on in this guidance.
- **Phase 2: Establishing the team** – is a more formal period with initial meetings and the active involvement of a wider group.
- **Phase 3: Planning the review** – moves this group into a period of active planning and ensuring resources are available for the study.
- **Phase 4: Undertaking research** – sees the study take place, with regular meetings between review and data groups.
- **Phase 5: Preparing and disseminating findings** – sees the preparation of findings and their dissemination, with ongoing actions set with partners across the healthcare systems, including statutory and third sector groups.
Alcohol Deaths Reviews

REVIEW ORGANISATION

For efficient organisation of the review, AFS recommends project teams consist of two groups.

- The **data group** analyses files and is responsible for the technical aspects of the review.
- The **review group** steers the content of the review, considers the data to generate findings and is responsible for compiling the public and private reports for publication.

More information on the NHS Caldicott Subgroup follows on the next page.

The data group generates data for the study, from public information and individual case files. Data group members should have experience of analysing or researching patient records and may consist of Public Health Analysts, Registrars or ADP team members with experience of research or data analysis. Prior knowledge of addictions should not be a requirement for data group members. Discussion with the review group can bridge any gaps in knowledge.

The review group’s purpose is to be both a sounding board for the analysts in the data group, and to steer the study through its phases. The review group should be multidisciplinary and have a longer-term view of the study and its use. Members of the review group should be people from across treatment levels, both statutory and third sector, with the power to make changes recommended by the review. The review group should also include named responsible figures for the Caldicott application.

Sometimes there may be members of the project team who are part of both groups. For example there may be ADP staff whose analytic skills are useful in the data group, but who can also provide input.
on community addiction support systems through the review group.

Due to regulations around confidentiality and data handling, all members of the project team will have to be staff members employed within a statutory or third sector organisation.

Because of the requirement that personal NHS data is analysed only by NHS staff (see p20 for more on Caldicott processes), there is a requirement to have an NHS Caldicott subgroup which involves NHS staff from the review and data groups. This subgroup can then analyse Caldicott-sensitive sources and present aggregated information about interaction with NHS services for use in the final reports.

As part of the research towards this guidance, AFS also examined how lived and living experience can be involved in alcohol death reviews. Involving these experiences is likely to happen in two ways.

First is involving people with a connection to someone whose files are examined in the review. To date this has not been a feature of any of the alcohol death reviews we know of, but there are examples of practice in other areas such as drug deaths reviews and suicide reviews. We consulted bereavement support specialists who advised that the process of recollecting a person’s life can be beneficial for people who have lost someone, it can also be acutely difficult for those involved. More information is available on p26.

The second means of involving lived or living experience is in service design and improvement, which AFS actively encourages review groups to do as part of their action planning. This can be helped by involving recovery services throughout the review process, and by making sure there is time and practical support to involve people with lived experience as action plans are generated. More information is included on p28-29.

“Right from the start we had to ask ourselves ‘who is this for?’”

PREVIOUS REVIEWER
Early on in the process of reviewing, it’s worth considering a few key issues that can inform the work you may do.

First is how to resource the project. Reviews are best undertaken with dedicated analyst time, which is often most easily accessed through NHS Public Health, but ADPs may be able to support the review too. Analysts, as noted before, can be Public Health Analysts, Registrars or ADP team members experienced in quality review, or other roles with experience in systematic analysis from case files.

The amount of file analysis time required varies, but with adequate planning and discussion with relevant parties, it can be agreed to dedicate two or three days per month of an analyst’s time to the work over the course of the review, to examine case files. If using a cohort study (see the cohort study section for more information on p18-19), files for the largest areas may be prioritised for the analyst’s input, with additional support from the data group to undertake study in other areas.

AFS recommends that discussions between Public Health and ADP partners begin early, so that shared interests and possible resources can be identified from the outset.

Analyst, or researcher time, is not an absolute necessity for conducting a review, though it almost guarantees a quicker, easier process for all involved and reduces the timetable for review by months or years. There have been reviews in the past that have not used dedicated analyst time, but these have taken substantially longer than 12 months to complete and those who were involved strongly suggest that dedicated resourcing would be necessary.

If analyst time is not available, reviews may also be undertaken by groups of staff, with members contributing time to the process as available. This has been done in the past, though it requires careful planning and we would recommend having a lead member, or two, who can liaise with AFS to help steer the process.

A second consideration is the time of year for scheduling the phases of the review. Some NHS boards are able to provide updates on deaths throughout the year, others are not. NRS usually release alcohol deaths data in June each year, and in some areas this is the point at which data on individual cases can begin to be analysed. Data may also be obtained from Public Health Scotland’s Data and Intelligence team (previously ISD).

When you have discussed the idea with colleagues it is worth formally approaching other ADP and Public Health partners to see how it can fit in with existing work, or could be appropriately scheduled.
AFS can offer in-person support at crucial points to ADP and Public Health teams undertaking alcohol death reviews. First in attending early project meetings to help frame the issue by providing information about alcohol deaths and how they relate to other areas of work, and give an overview of much of the detail of this guidance.

Then as the project continues AFS facilitate the Alcohol Death Researcher Network (ADRN, see p27) – a resource for researchers involved in projects. We can also help answer questions or put your team in contact with people around Scotland whose experience may be of use if you encounter problems. This can extend to any specificities your alcohol death review may have.

Drug and alcohol death reviews have major structural differences. Make sure you can learn from drug deaths work, but be aware of the differences in reporting, source material and how the substances affect people.

Consider in your initial thinking what resources and supports are available: ADPs, Public Health and other figures can and should collaborate on alcohol death reviews.

Consider analyst time requirements at an early stage and involve both ADP(s) and NHS public health teams in review planning so that analyst time can be resourced and coordinated.

“Had one agency not been involved in care, a person might have died sooner.”

AN INTERVIEWEE ON THE IMPORTANCE OF MULTI-AGENCY REVIEW GROUPS
AFS recommends every project team includes a data group and a review group. Data groups undertake the research, while review groups offer guidance and reviews the findings. The memberships are not exclusive, and the two groups should meet regularly, but there are usually reviewers with no direct role in undertaking research.

The two-tiered approach is a positive feature of reviewing. It allows for discussion, more detailed interrogation of the data provided by research, and facilitates an easier dissemination of findings at the wider level.

The review group’s interactions with the data group are the cornerstone of successful reviews. This section examines the qualities that can help members of both groups succeed.

Those who have already undertaken reviews speak of the need to involve a range of professional outlooks and experiences in review groups. With reviews frequently attracting high levels of interest from professionals in the field, the formation of the group is an exciting opportunity to involve a range of perspectives.

Drawing on people’s experiences, we suggest that the review group involves those including, but not limited to:

- Third sector workers;
- Nursing staff from acute, general and psychiatric backgrounds;
- Doctors from acute, general and psychiatric backgrounds;
- The Alcohol and Drug Partnership (ADP) Officials;
- Allied Health Professionals;
- Local specialist services including alcohol-related brain damage (ARBD) and detox facilities.

Data groups and review groups meet throughout the review process. From interviews with people experienced in reviews, AFS recommends the following qualities are reflected in the review group:

- Experience of qualitative and quantitative research;
- Experience of analysing complex data;
- Professional experience of practice relating to alcohol misuse disorders;
- A non-judgmental, dispassionate understanding of personal behaviour in relation to alcohol misuse;
- Open-mindedness about the prospects for improving services;
- An interest in the wider application of the review’s findings, i.e. social issues;
- The ability to act as an advocate for the review’s findings in various settings and fields.

Data group members’ work relies on technical skill in analysis and/or research. Data group members do not need to have in-depth knowledge of alcohol deaths at the point they become involved, as this can be provided by other members of the review group.

The data group is directly responsible for undertaking the research: gaining Caldicott approval; sourcing data; analysing file records; collecting the data; and presenting it for analysis. It was repeatedly pointed out by interviewees that...
a grounding in addictions work, or even addictions research, is not a prerequisite for researchers as this can be provided by the review group.

Instead, data group members should have a proven track record working with NHS patient records, and involvement in research study on other projects. The technical skills involved in research include identifying datasets, analysing large volumes of complex and often disorganised patient data, and compiling results into usable forms.

Phase 2
Key points

A review is best undertaken with two groups; review and data, which complement each other through the process. These two groups form the project team.

Review group members should have knowledge of the problems the review deals with, from a range of disciplines and perspectives.

The data group needs previous experience with research, though not necessarily addictions or alcohol work – this knowledge can be provided by the review group, who can add context and insight to the data group’s findings.

“" We couldn’t have done this without (Public Health). ""
AN ADP INTERVIEWEE

“" Us neither. ""
A PUBLIC HEALTH INTERVIEWEE IN THE SAME AREA
Data sources

Case reviews can draw upon a number of data sources to assess how support for people at risk of dying can be improved through a range of settings and interventions.

National Records of Scotland (NRS) publish annual statistics on alcohol-specific deaths in June. This publication details the number of deaths across Scotland, broken down by health board/local authority area, age and sex. For ICD-10 Codes, see https://icd.who.int/browse10/2016/en

This data, plus information provided by each area’s Local Intelligence Support Team (LIST), from Public Health Scotland can be used to generate a local profile of alcohol deaths. LISTs, are active in every area of Scotland and can provide a range of personal data for cases which can be useful in building a local profile.

The second stage of alcohol death reviews is the case review, where individual case files are analysed to understand the circumstances of people whose deaths have been caused by alcohol. NHS Health Boards collect data on all deaths, organised by ICD-10 code, every week. This data may be used on a rolling basis through the year, but carries a risk of missing some deaths: as unascertained causes are not included in those releases, the NRS data in June is the most comprehensive available for the whole-year period.

Case reviews typically involve study of files...
from more than one setting, to generate the most complete picture possible of an individual's life. This involves primary care records, hospital records (typically SMR1 and SMR4 records of acute and psychiatric patient stays respectively), third sector notes, social work records, as well as housing and police where appropriate.

Obviously, ensuring access to these records requires a degree of planning. This is covered later on in this guidance, but we recommend planning not just for the study areas, but the permissions required and how these can be obtained. ADPs may play a role in working with commissioned services, and should examine their data-sharing protocols as necessary. Doing this well in advance of seeking Caldicott permissions helps ensure that process runs smoothly, allowing the study to proceed as quickly and efficiently as possible.

Local profiles

Local profiles give demographic context to the overall problem of alcohol deaths. Having a sense of the gender split, age, ethnic background and service interaction can be useful in shaping the cohort and identifying particular areas for study.

Local profiles of alcohol deaths can be generated using data from NRS, which can be broken down to health board or local authority level, and Public Health Scotland. This is not named patient data, and so requires no specific Caldicott approval; it can be undertaken in parallel with seeking Caldicott approval for the case review.

The local profile can be a useful first part of the review report, giving context of your local area(s) with reference to the rest of Scotland and/or other parts of the UK with similar socioeconomic profiles.

If your area already generates an annual alcohol profile then it could be helpful to include data from the alcohol death local profile in this, even in years where you are not conducting a full case review.

Cohort studies

Cohort studies are used to analyse, in depth, a representative sample of cases where the total number of cases is too high to be examined in full. While case reviews are always useful, deciding whether or not to use a cohort is a matter for the teams in each area.

AFS advises that project teams refer to the number of deaths in ADP areas when deciding on whether or not to use cohort studies. Because ADP areas correlate with local authority areas, determining cohorts at this level allows results to easily link with support from statutory local authority and third sector services.

Cohort studies need to analyse 30-50% of cases in the area in the year of study, based on experience in previous reviews. With AFS’s research showing that a dedicated analyst’s time should allow analysis of 50-60 files over several months, towards a total review time of 12-16 months, this can be used to assess whether or not a cohort may be used in an area.

• If an ADP area has fewer than 50 deaths it should be able to analyse all the alcohol-specific deaths that year with dedicated analyst time.
• If an ADP area has more than 50 deaths it may be necessary to use a cohort of 30-50% of death cases in that ADP area, and analyst(s) time should be considered accordingly.
Establishing a cohort

Cohorts should be representative of the general population who died in the area. Look at the NRS and Public Health Scotland data for your area in the year of study and evaluate:

- Age at death;
- Sex;
- Race and ethnicity;
- Level of deprivation (Scottish Index of Multiple Deprivation (SIMD) of home address).10

The cohort demographics should mirror, as closely as possible, the demographics for the total population who died in the year of study. Coding named person data for demographics can help this process. SIMD data can be accessed for known postcodes, across a number of deprivation domains.

There may be other factors that influence individual cases’ inclusion in the cohort. For example, availability of data; if it is not possible to access GP patient records, or if the review group believes that accessing notes from acute hospital admissions would be prohibitively difficult, there may be grounds to exclude individual cases.

If this decision is taken, we would encourage the review group to raise the issue in discussions with AFS, so as to identify gaps in our knowledge at the national level and possible areas for future study.

Time needed for case file reviews

Proper time needs to be given to consider the findings from case files. The review and data groups should collectively discuss the areas for study and identify specific data items for examination in files.

With sufficient resources in place, it should be possible to complete a review in 12-16 months, with approximately 4 months
planning the project, 6 months undertaking the research, and 2 months compiling and considering the final report.

Experienced researchers suggest that with sufficient planning and a useful question set, they can analyse the NHS primary care and acute records of 3-4 patients per day. This can then be supplemented with information provided by third sector and other statutory partners as requested in a batch at the start of the research period.

**Caldicott approval and records access**

Obtaining Caldicott permission is an essential part of the review process, and can be helped by enlisting the support of an experienced researcher or analyst, and planning applications early.

Some of the information used in reviews is publicly available, and therefore requires no Caldicott approval. NRS data is public, and needs no approval to form part of a review. “Named Person” data for the case file study will require Caldicott approval, however, to ensure patient confidentiality is protected.

Named person data identifies the particular details of a person’s individual case. Patient records in any setting, as well as files from other settings, all count as named person data.

**Caldicott Approval**

Using NHS-held named person data requires approval under Caldicott information sharing protocols. Requests are reviewed by the Caldicott Guardian for each NHS Health Board, with requests typically considered at a regular monthly meeting.

More information about the NHS Scotland Caldicott processes can be found through your local Caldicott Guardian.

If your study has input from public health researchers it is likely they can help guide this process. In some cases Caldicott Guardians have existing links with other figures in public health, which can help to smooth the process significantly.

Caldicott applications detail the data being requested, how it will be stored, the arrangements for sharing it with any partner organisations, and the reasons for approving the request under the Caldicott principles.
It is important to prepare an application carefully, after planning what data will be requested, so that the process can be as smooth as possible. Itemising the data points as other reviews have will help with this process (this is covered in the next section).

It is helpful to consider a publication plan ahead of submitting Caldicott approval, as there may be implications if named person data were to be published, even in anonymised format (for example where numbers are small enough to enable individuals to be identified).

Obtaining Caldicott approval has been identified as the single biggest hurdle before starting the research for many reviews in the past. Having an early discussion with someone in the Caldicott office can help, as can having the time of an experienced researcher in the data group, and ensuring you involve people from relevant data sources involved in the process early on.

Caldicott meetings vary by area but it can take anywhere between several weeks and several months to clear the process. Make sure you contact the relevant Caldicott Guardian for your area early in the process to make them aware of the planned research and ask for any guidance they can offer in preparing your application.

Caldicott guardians can be contacted locally, and members of the data group should be able to assist with this.

Caldicott approval lasts for a certain period you apply for, and so your review could be ‘timed out’ if it overruns. This is not necessarily, in practice, a major problem but can be avoided by having a considered timescale for the work, factoring in resources available and planning for contingencies. If there is an overrun it should be possible to request an extension in good time, and this should be considered sooner rather than later if it seems like it may be necessary.

Research plan

Having a research plan can be a significant help in establishing clear timescales for the project and ensuring the relationship between review and data groups is clear from the outset. We recommend reviewing files on a rolling basis, with monthly or bimonthly meetings of the review group to consider data as it becomes available, in the form of key updates from case files.

Consistently reviewing files gives the review group an opportunity to get a sense of any issues as they become apparent, and to become familiar with the project’s output ahead of compiling and responding to the report. We have no specific recommendation on how often the review and data groups should meet while the research is taking place, though some interviewees suggested that at least once during the process would be helpful. Instead the review group can continue to consider findings prepared by analysts from the data group on a monthly basis.

A research plan can also help in ensuring the work remains on-track. As individual patient records vary substantially in size, it is possible to check early on in the process whether or not the timescales may have to be adapted. This can free up review group time, and allow the project to continue without becoming onerous for those involved. Similarly, a research plan allows the data group to check their progress and identify possible issues ahead of time.
Social work, police and other statutory records

Local arrangements for data sharing should be examined early on in planning, and consulted in cases where data from other statutory records are sought. Given the specific nature of alcohol death reviews it is unlikely that workers from non-addictions settings would be interested in attending every review meeting. Therefore consideration should be given at an early stage as to how to obtain data as easily as possible and allow for timely input from other agencies as findings are considered.

Third sector records

Including third sector records in review studies is extremely valuable, given the significant role third sector agencies play in facilitating recovery and avoiding death. If it is possible to include third sector treatment providers in the review group this would be especially helpful; these representatives can help facilitate access to records for the purpose of the review, in line with General Data Protection Regulation (GDPR) and other data-sharing protocols. These may already be in place under ADP commissioning protocols.

Ensuring your review group includes senior representatives from commissioned third sector services, statutory agencies and other settings whose data will be used in the review can be an enormous help in obtaining Caldicott approval and planning the study. In turn it can help to ensure findings are publicised and implemented.

Establishing and testing the question set

The project team should work collectively to take areas of concern and map them against data items, before turning this into a question set that can be used by researchers or analysts to analyse individual files.

Any case review involves research into individual cases, and so a question set is an ideal way to ensure all cases are evaluated to the same standard. Planning the question set with the review group also allows for a wide range of questions to be met.

Beginning with a map of data items and sources can be helpful (figure 7).

A data map can then be turned into a question set, to allow data on cases to be collected across different settings more efficiently. For example, a question set for required data from third sector sources could be developed so that when a case is shown to have contact, this can be sent through the relevant service manager on the review group to that service, who can quickly gather the information.

It is helpful to categorise data items in broader categories. The 2013 Glasgow Review included the following data item criteria:

- Demographics
- Alcohol problem and contact with services
- ABI screening and detection of alcohol problems
- Health and contact with acute services
- Alcohol relapse prevention medication and vitamins
- Alcohol detox
- Liver transplant
- Other substances
- Services referred to and attended
- Social issues
- GP contact
- Police contact
- Other Social Work contacts
- Miscellaneous
Early-stage data map

Case 1
John Doe

Public Health Scotland/NRS Data
- Name (forename/surname)
- Age at death
- Date of birth
- Residence type

GP Records
- ABI in past 10 years?
- GP contact in past 5 years?
- Alcohol noted as problem by GP?

Acute Records
- Acamprosate prescribed ever?
- Inpatient detox?
- ARBD assessment?

Police
- Fire service contact in past 3 years?
- Any police contact in past 3 years?

Third Sector/Statutory
- When referred?
- Ever contacted?
- Reduced consumption?

Figure 7 Example of early-stage data map
If your review includes third sector files, treatment for alcohol-related illnesses, ARBD or focuses on other demographic groups, it would be useful to itemise these data within separate categories.

**Testing the question set**

Trialling your question set on a limited number of files can be useful, especially in areas using a cohort study because of high numbers of deaths. Any gaps in data or other issues can be addressed through this pilot study, acting as a ‘dress rehearsal’ for the full review process, including seeking Caldicott approval and familiarisation with the research processes for new researchers.

Findings from files in the pilot can still contribute to the overall review, but allow problems to be identified early in the process. Typically a pilot covering 20% of the cases to be covered in the cohort study is sufficient to resolve any issues. These results can be analysed by the review group as well, giving a sense of the way meetings can be carried out in future.

**Specialist studies**

While this guidance gives an overview of how to undertake reviews of alcohol deaths, some areas may want to undertake specialist study of an area of particular interest or concern to local partners.

These may include, but are not limited to: alcohol-related deaths; cases related to particular pathways such as ARBD or community detox; or cases from particular demographics.

Undertaking specialist studies within a review is by no means necessary, but can add weight to local understanding of particular issues. In practical terms, the process of special studies is no different to the usual review process; these practices would just be applied to a specific category of cases, perhaps as a sub-cohort.

If in doubt as to whether or not to undertake a specialist study, AFS recommends focusing on a general review for the first study, as specialist studies can be undertaken in more depth in the future with more experience to guide them.

We recommend that review groups consider any specialist study at the earliest stages of planning, as research planning and ethics processes need to take account of the specialist study’s needs.

AFS’s research indicates that ADPs or Health Boards with access to one researcher for the project can expect to review 50-60 case files in depth, supplemented by additional data from third sector and other statutory records. In ADPs or Health Boards with fewer deaths, there may be interest in reviewing files where the cause of death is alcohol-related, not just alcohol-specific.

Special studies can be considered from the earliest stages of planning and work on the local profile. This can allow for different ICD-10 codes to be gathered, for example those accounting for alcohol-related deaths under the ScotPHO definition laid out in the 2018 *Burden of Disease Attributable to Alcohol Consumption* report;¹¹ or cases of suicide (codes X60-X84).¹²

Given the much broader scope of alcohol-related deaths, both in terms of medical specialty and numbers – with about four

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¹² ICD-10 Codes available at [https://icd.who.int/browse10/2016/en](https://icd.who.int/browse10/2016/en)
times as many alcohol-related deaths as specific – it is important to be clear on what would be studied in your area, if you choose to pursue a study of alcohol-related deaths.

ScotPHO’s 2018 Burden of Disease study can be instructive here. There are 30 alcohol-related conditions detailed in this report, under categories that can guide project teams’ thinking such as “malignant neoplasms” (cancers), “cardiovascular disease,” and injuries both intentional and unintentional. These kinds of special studies, alongside a full review of alcohol-specific deaths, can help bring an alcohol focus to other elements of public health work, for example suicide reviews or heart disease.

Having identified the causes of death you would like to include in the review, the ICD-10 codes listed in the ScotPHO report can be used in a process parallel with the main review, using the same methodology described in this guidance.

It can be useful to identify at an early stage how the caseload of a specialist study would fit with the main report into alcohol-specific deaths. For example if two analysts are required to evaluate the combined 90 case files required for the alcohol-specific review, but their combined capacity is closer to 100-120 files, it may be possible to undertake a specialist study of 10-30 alcohol-related deaths.

Phase 3 Key points

Drafting a local profile with NRS and Public Health Scotland data can give overarching clinical and demographic data. This in turn can be useful for planning the rest of the study.

Consider the questions people on the project team would like to examine, and which data sources these relate to.

Map data sources early on so access can be arranged and the relevant people involved in the review group. This will help in preparing your Caldicott application.

Consider early on if your locality needs a cohort study, referring to the guidance on p18-19.

Consider at this stage how the review will be used – which elements may be published, how it might work alongside other strategic initiatives, and how any recommendations will be implemented.

Identify if you will undertake any specialist study early on, so that the review planning process can be applied to this subset as well.
PHASE 4: UNDERTAKING THE RESEARCH

Once you have Caldicott approval and the data group is in place, you can start the process of researching files.

Alcohol death reviews rely on data from multiple sources:

**NHS Primary Care** patient records are typically held post-mortem, in hard copy, at local Practitioner Services facilities, often the same site already known to drug deaths researchers. Access to these records tends to require in-person attendance as files cannot leave the premises. It can be helpful to liaise with researchers with drug death review experience as they may have existing relationships with local staff.

**NHS Acute Records** are held in different places across different sites. In some areas they are held centrally post-mortem, in others they are kept in hospitals. In either case, having an effective working relationship with staff at various sites is crucial in facilitating access to records. Having clinical input, from nurses and doctors directly involved in treatment, on the review and/or data group can assist with this process. Some areas have e-health programmes that can facilitate access to this data.

**Social Work Records** are held by local authorities. There is no national social work database, and record availability, electronically or on paper, varies by area. It is worth consulting with social work colleagues on your review group to find out how best to link the data – typically a CHI number or NI number is most helpful, both of which should feature in NHS data. Access to these records, if they are held physically, typically involves visiting an archive.

**Third Sector Records** are often held electronically, and may be accessible under data-sharing agreements described as part of the service contract if commissioned through an ADP or Health and Social Care Partnership (HSCP.) For services not commissioned through an ADP, for example an independent treatment service, it is worth considering inviting someone from that organisation to the review group and establishing a data sharing agreement for the purposes of the review, which can satisfy Caldicott guidelines.

**Other Statutory Records** including housing, police records and others. As local data sharing agreements vary, and points of contact are crucial, we advise considering how to involve these sources early in project planning, so contacts can be made if needed.

Involving people who are bereaved

AFS has spoken with charities and groups that support people bereaved by addiction. To date, none of the alcohol death reviews we are aware of in Scotland have had direct input from family members or other people in the life of the person who died.

Understandably people are interested to see how reviews might include the perspectives of people who have been bereaved. Currently, drug death reviews sometimes allow people to contribute their understanding of events to the review, but there are no standards AFS is aware of to guide families’ involvement in alcohol death reviews.
The timing of involvement for people who have been bereaved is sensitive, as is the question of how best to support people. This should be handled on a case-by-case basis if it’s decided to involve this element of experience in the review. If it is, we advise consulting with local bereavement support groups and organisations in your area, many of which can be reached through Scottish Families Affected by Alcohol and Drugs, at https://www.sfad.org.uk/service-directory.

Researcher wellbeing and the Alcohol Death Researchers’ Network (ADRN)

The researchers interviewed for this project were unanimous in their belief in the potential of alcohol death reviews, and took pride in their work to deliver them. They felt these reviews were an opportunity to learn lessons and inform improvements that might help to prevent other people losing their lives in the future.

That being said, this is difficult work, emotionally and technically. Researchers can spend significant time reading files that, by the nature of the project, often contain distressing details and extremely difficult circumstances. While technical skill is an important part of researchers’ suitability, their emotional wellbeing has to be catered for, too.

Alcohol Focus Scotland facilitates the Alcohol Death Researchers’ Network (ADRN), which meets bimonthly. This is a group for people directly involved in research, and functions as a forum to discuss technical challenges but also, while respecting confidentiality, the challenges of the work. This was highlighted as a positive intervention by experienced researchers, and can be accessed anytime by contacting AFS.

Making sure data group members have the opportunity to discuss their work with colleagues in the wider review group is important too. Research can be frustrating, and the detail of some cases may present emotional challenges for staff – make sure that there are adequate line management and support structures in place for the data group. The Alcohol Death Researchers’ Network is also available for support.

Phase 4

Key points

The review group should meet regularly through the research period as findings become available, with input from data group analysts as required. It can be helpful to have at least one project team meeting, where all members of the data and review groups are present, as research is carried out.

Set up parallel structures for data to be managed, i.e. if only NHS staff can see Caldicott-approved records, have them meet separately to consider protected data and have anonymised findings presented to the review group for consideration when appropriate.

The data group can present a series of files that have been worked on, for consideration by the review group.

Statutory representatives from other agencies can be involved at different stages, as required.

Teams can use the Alcohol Deaths Researchers’ Network as an ongoing resource for technical expertise and support.
PHASE 5: PREPARING AND DISSEMINATING THE FINDINGS

After the research is concluded, findings can be drawn together for publication. AFS advises including a section on publication in your research plan, for several reasons.

Firstly, a publication plan encourages participants across different organisations to consider at an early stage how the results of the research will be used, and who their target audiences will be. Secondly, it helps establish how data will be used for each report. Thirdly, it allows non-public reports to be tailored to the needs of those who will use them, across professional boundaries.

Public and private reporting

An important issue to consider as part of the publication plan is how data will be used. It can be easier for Caldicott approval to have two reports: one describing the interactions people had with services before they died – which remains private, and provides specific learning for operational purposes – and a second, shorter, public report that highlights the overall lessons learned, alongside the local profile.

This approach can allow smoother Caldicott approval, usually by ensuring that no personal information will be used in the public-facing report. Individual data, for example anonymised case studies, can still be used in the private systematic report, but would be completely absent from the public version.

The public version may then be used as part of public awareness campaigns across the area to raise the profile of alcohol deaths. The private version can be used by services and partners to identify areas where support could be tailored to people at risk of dying.

Preparing the reports

The review group plays an important role at this point. If the process has been well-planned and there are timescales and expectations agreed and in place, this helps ensure the report will be a constructive document that blends reflection with forward thinking and can bring significant changes to prevent future deaths.

Several experienced researchers suggested in the course of their interviews that they felt learning from cases of deaths in other categories, such as drug deaths, could be complicated by blaming cultures. Alcohol death reviews were highlighted by all interviewees as having enormous promise for avoiding future deaths, but several also highlighted the need to make sure that they are approached with the right mind set.

Alcohol death reviews take a systematic view of the issues affecting each case, including personal circumstances and histories, and interactions with systems of care. They should be open-minded, rather than seeking to find fault or blame. If, on reflection, the review indicates gaps in care structures, these should be discussed collegially and with an emphasis on identifying constructive solutions, not simply problems.
It can be useful to include on the review group a representative from each area of the system with responsibility for implementing changes based on the report. Doing so can allow this person to feed back through professional channels, making for easier communication when the report is due for publication.

**Effecting change**

All previous reviews of alcohol deaths in Scotland have identified structural changes that can be made across systems in their area to prevent future deaths. How far the review goes in identifying solutions to identified problems is a matter for local teams, though it can be helpful to consider two basic options.

The first kind of report highlights only the concerns arising from the research such as different participation rates in different programmes, access to interventions or retention rates. These are then left to teams across the healthcare system in that area to consider, perhaps with ongoing involvement from senior figures.

The second kind of report has all the above detail, but also includes a plan for action including the various partners. This may take the form of a three-year plan with identifiable actions and outcomes, and means of evaluating the changes that have taken place. The action plan may not necessarily accompany the initial report’s publication, but could follow within a few months while the team has the findings in mind and can discuss it with colleagues across the system.

Where a report includes an action plan this is an excellent opportunity to involve lived and living experience. These views are vital in evaluating where practical changes, complex or simple, can be made to help people access support in the future. AFS recommends involving people with experience of Recovery-Oriented Systems of Care in the review group, and then involving recovery services and wider supports in the process of action planning. This can ensure the review is publicised among people who may directly benefit from its findings.

**Strategic priorities**

Areas where reviews have taken place have identified broadly similar areas of strategic priority. Changes that have been recommended fall predominantly into a few categories.

Some recommendations are around data and communication – how information about a person's alcohol use, or misuse, is recorded and in turn how services communicate this to each other. Dealing with these challenges involves close work with staff and services, and may involve training but likely has few resource implications. One project team began to look more closely at links between community addictions treatment providers and other statutory services as a result of their study.

Then there are recommendations around the care of people whose needs the review identifies as not currently being met. These can include new services or changing pathways, and fixing these systemic issues is likely to take time and consideration, possibly with a bearing on commissioning processes and resource implications for existing services. Recommendations to review pathways for people at risk of an alcohol death presenting at hospital were a feature of several reviews.

The third category accounts for different approaches to treatment or prevention.
– incorporating novel approaches to treatment in existing services, or resourcing the acquisition of new technology along with the training of staff and development of new pathways for people in the new services. This may involve considerable resource implications, and again take some time to plan for. Early detection and intervention approaches, including the use of Fibroscan technology, have been seen in past reviews.

A positive feature of existing death reviews has been their capacity to highlight the key factors affecting people at risk of dying by alcohol. How the findings are interpreted is ultimately up to teams in the local area, but can be helped by a cohesive message emerging from a multidisciplinary review group.

"The first time (the review) is carried out people are so grateful to have evidence, you’re giving yourselves the evidence to take these ideas forward."
REFERENCES


7. For ICD-10 Codes, see available at https://icd.who.int/browse10/2016/en