

APPCOG CO Data Workshop: Discussion & Outcomes

1 April 2021, 9:30 – 11:00

Chaired by Baroness Finlay

Sponsored by the Gas Safety Trust

An event to analyse and examine the current sources of data on CO incidents and exposure; and bring together views on what improvements can be made. It is widely accepted that improved data on carbon monoxide would help CO victims to be better supported by healthcare workers. Access to better data on CO would benefit many parties, assisting GDNs in targeting their resources effectively, and enabling nationwide research projects. If records can be coordinated and aligned, trends and prevalence of CO incidents could be identified, and effective pathways for data could be established. Ultimately, better data on CO would benefit gas consumers and society.

Findings and Next Steps

There are established, tried and test methods for Gas Distributions Networks and NHS bodies to share data, as has been done in the National Poisons Information Service (NPIS) study (see Appendix 1 and Dr Gill Jackson presentation). Compliance with GDPR can be achieved by taking the legally prescribed steps.

The existing data available on carbon monoxide shows valuable trends: for example in terms of cross over with vulnerability factors, and revealing the often unusual location of fatalities; such as those in outhouses, sheds and aboard boats. Gaining better data on CO can help to broaden our understanding of risks, in addition to demonstrating the prevalence of harm caused by CO and generating political pressure.

In order to create meaningful, wide reaching data and improve future practices, a holistic approach is required. As we have seen, a variety of different organisations might interact with a CO incident, and all collect varying data. If we seek to bring this data together, firstly it must be standardised and of a reliable quality to be of use.

Key requirements of a functional CO data system:

- CO protocol for first responders
- Set categories of data: what to record
- Standard definitions of information for data coding
- Data collectors must be aware and educated
- Agreement from relevant bodies to report data collected

The better CO data initiative will progress by conducting a deeper analysis of the existing CO data systems to identify gaps and opportunities. Current CO data systems will be compared with other areas of public safety, and CO data practices in other nations. After this intelligence has been gathered, we will collaborate with wider stakeholders to create a proposal for developing a functional CO data system.

Background

The event explored how current incident data on CO is collected, how the quality and coverage of this data could be improved, and where there may be opportunities to improve prevention, detection, diagnosis and treatment of CO poisoning through improved data sharing and collaboration.

There are many public bodies which collect data on CO incidents and exposures, these include:

1. Health and Safety Executive (HSE)
2. Office of National Statistics (ONS)
3. Gas Distribution Networks (GDNs)
4. National Gas Incident System (NGIS)
5. National Poisons Information Service
6. Fire and Rescue Service (FRS), reporting to the Home Office
7. Gas Emergency Service
8. Gas Safe Register
9. Healthcare – NHS and Private
10. Police
11. Boat Safety Scheme

Organisations collect data in a range of ways, and often have differing legal obligations as to what they record. Some organisations share their data, for example the Fire and Rescue Service report to the Home Office each quarter, but this is not universal. There is no set protocol for responding to a CO incident, or for following up to see what the outcome of an incident has been. Whether or not 'near misses' are, or should be, recorded is also unclear, and appears to vary across different areas and bodies.

In short, the data on CO is piecemeal and disjointed. This creates several issues:

- Accurately identifying the prevalence of CO incidents (and harm incurred) across the UK is very difficult
- Each record contains only one piece of the story; meaning that outcomes are often unknown, and there is no feedback which the bodies and systems that respond to CO incidents could use to gauge effectivity
- Individuals affected by CO exposure struggle to access treatment
- CO research is generally limited to studies covering small areas, as opposed to drawing on an existing nationwide data set
- Measuring the impact of public safety initiatives is hindered

Event Overview

The event was chaired and opened by Baroness Finlay, who thanked attendees and the expert speakers. Baroness Finlay noted that the APPCOG has been calling for better data on CO for many years, this would benefit survivors and help us to understand the extent and impact of low level CO exposure across the UK.

Expert Speakers: Current practices for CO incident data collection, recording and sharing

Steve Dacre, Vulnerability and Innovation Lead, Northern Gas Networks (NGN)

Steve Dacre demonstrated the Vulnerability and Data Visualisation tool that NGN has developed to bring their data analysis to life. The tool combines open source data from the ONS on vulnerability, indices of multiple deprivation (IMD), fuel poverty data, EPC ratings, and households with a child under 12 years old; which is then overlaid with the data NGN hold on CO call outs, where NGN engineers have attended an incident due to a call from a member of the public. It is noted that in such situations, engineers may not be able to confirm the presence of CO and hence incidents where CO is suspected but not confirmed are included.

Displaying data visually has enhanced NGN's understanding of the scale of the CO problem, and how different factors interact, leading to increased risk. This visualisation tool can be used down to a postcode level, providing a granular overview of the area that NGN oversees.

In January NGN commissioned some further data research, and yesterday agreed a separate research project looking at effective CO messaging for all consumers. Steve has recently implemented some internal system changes to streamline NGN's CO data practices; these will enable better extraction of CO data so that it can be added to the visualisation tool in a more meaningful and insightful way.

Steve welcomed further collaboration with the fire service, NHS, and other parties that hold data on CO. NGN understand that by visualising data, CO exposures, deaths and hospitalisations can be reduced. Combining research, statistics and awareness is at the core of NGN's work, and collaboration with others is key to achieving success. The visualisation tool has been designed to be immersive and user friendly, creating an informative resource and giving the 'silent killer' no where to hide.

Mark Hazelton, Trustee Gas Safety Trust & ex-NFCC CO Safety Lead and Fire and Rescue

Mark provided an insight into the fire and rescues services (FRS) data practices. When FRS attend any incident, they take notes at the scene then once back at station complete a Home Office national recording form. However, there is not a standard way of recording CO incident data within this process. Practices differ widely; the most scrupulous report might include background information such as the source of the CO, but this is far from common. In the public's mind carbon monoxide is generally associated with gas, however of course CO can be generated by solid fuel, through bad building practices and from entry from adjacent premises.

In recent years there have been two pushes to analyse the FRS data on CO. In 2017, a trawl of data held by London Fire Brigade (LFB) showed that CO was mentioned in 39 cases of deaths, however as the FRS do not follow up cases with the health service or coroners it is not known if exposure was the cause of, or contributed to death. There were 100 incidents non-fatal CO incidents, and CO incidents showed an upward trajectory over time, whereas incidents of fires have been reducing for many years. Attempts were made to refine the data but there were challenges, due to the manner of collection. More recently Patrick Meehan, (Ex-NFCC CO Safety Lead) issued several Freedom of Information requests which returned a wealth of data on CO incidents attended by the FRS, however once again the quality of data captured was unreliable. Surprisingly, areas with matching external factors such as demographics, fuel types, IMD, cooking use etc. did not show matching, or similar, data in relation to CO incidents attended by the FRS. This is most likely due to the adhoc nature of CO incident recording.

Mark notes that not just FRS but all emergency services and first responders can be key sources of CO incident data. Quality detailed incident data is the key to building the case for political action on CO, and evidences the need to dedicate resources to CO safety.

Dr Gill Jackson, National Poisons Information Service (NPIS)

Gill introduced the UK NPIS, which is the primary source of poisons information in the UK, and has registered users in over 98 countries. It comprises of four poisons centres across the UK and a UK network of consultant toxicologists, who contribute to TOXBASE content and support the provision of a national helpline, providing advice to healthcare professionals across the UK. TOXBASE is a poison information database with over 20,000 entries, which is free for NHS facilities to use. Since 1999 it has been UK Healthcare policy that doctors and nurses should first consult TOXBASE when treating a poisoned patient.

Over four years, almost three thousand cases of CO exposures have been reported to NPIS, these came mainly from hospitals but also from primary care, telephone triage and the emergency services. NPIS data set transcends all NHS services across the UK, and a review of CO data has been submitted to the Journal of Public Health. The paper outlines the unique perspective that the NPIS data can provide, including the source of exposure (which is mainly faulty boilers); the use of CO alarm alerts when reported, vulnerable factors and COHb concentrations.

Summary stats from SGN carbon monoxide data:

- Approx 14,000 CO call outs each year
- 300 – 600 confirmed CO exposures per year (extremely important as a reliable source of confirmed CO exposures)
- 1200 – 1500 suspected CO exposures per year

Data sharing: Scotland is in a unique position, as all the gas distribution data is held by one GDN, and all healthcare data is in one place with NHS National Services Scotland. To link the data sets, eDRIS (Electronic Database Research Innovation Services) can be used, to process and return data in an anonymised format for analysis.

Information governance and research ethics must still be addressed, even with anonymised data set. SGN and NHS Lothian completed a three stage process to ensure compliance with their obligations, as detailed in Appendix 1. To further increase the quality and scope of this combined data, Gill hopes to next include information from the Health Data Research UK Scotland, on social and demographic statistics and vulnerability.

Improving practices: There are many valuable groups of data in the UK. To move forward here, it will be essential to establish what each of these data sets should 'ask'. To enhance their existing intelligence, GDNs could consider collecting wider data, for example ages and vulnerability of every person in the household, details of CO alarms, including the power supply (battery or mains), and the age of boilers. Once we have the data sets, there is a process where they can be linked.

A further issue is that not all NHS datasets across the UK are linked as they are in Scotland. A potential method for getting answers to the right questions might be for the person impacted by CO to become the link for the CO data. The individual could be referred to a helpline, where their information can be recorded on a central repository.

Workshop Question Discussions

Q1: What benefits can better data on CO bring?

- Gas Distribution Networks can benefit from understanding how best to target resources and campaigns, identifying risk and measuring the impact of their work
- Survivors of CO exposure would benefit by being able to evidence their experience and hence access proper treatment in healthcare
- Medics could develop a better understanding of the impacts of high and low level exposure, to diagnose and treat survivors effectively; and gain feedback on what treatment works to reach better healthcare outcomes
- Researchers could conduct studies of wider scope and participants; producing more reliable results and findings
- Policy makers would be able to understand the impact of CO in a more accurate way, leading to more effective policy on CO
- The public would be more aware of the risks of CO if the true size of the problem was known

One of the key benefits better data on carbon monoxide would bring is evidencing the true scale of the harm caused by CO in the UK each year, and the human and economic cost of inaction. Currently, in healthcare and research there is a perception that there is low prevalence of people who have been exposed to CO, due to an inability to gain accurate CO readings, either at source or internally in blood or breath. This means that it can be difficult to evidence the severity of the problem and the need for good research on causes and preventative actions. Accurate data on CO could build the political will required for policy change, and demonstrate the need for further investigation.

Q2 What data is needed?

- Demographics: age, location, property tenure, living circumstances, vulnerability considerations, PSR registrant – open source data can satisfy some of these factors
- CO Source: appliance (or other source) type and age, service history
- CO levels: atmospheric, breath, blood; and time that readings have been taken
- Proven or suspected incident, how CO was identified
- Risk resolved, action(s) taken, review process
- Alarm type and position in room; taking the alarm as evidence if safe to do so
- Limits on data capture: time, resources, knowledge

Publicly available data

Not all data needs to be collected at source by first responders or other bodies. Data in relation to vulnerability, indices of multiple deprivation (IMD), fuel poverty, EPC ratings, and households with a child under 12 years old can all be accessed from open sources, as highlighted by Steve Dacre (see expert speakers section above). To assist modelling of future data collection practices, there may be value in assessing what is critical and unique data in relation to a CO exposure incident, and what data already exists in this form.

When making a report via RIDDOR there are standard categories of data, however this system doesn't cover solid fuel or domestic incidents. When seeking to develop a future system for CO data, RIDDOR categories should be considered. Please see the attached briefing note from the Health and Safety Executive (HSE).

Potential for CO alarms to provide data

Current CO exposure data is largely based on either an alarm triggering or the person exhibiting extreme symptoms. Smart CO alarms can provide a wealth of data, which in some models can be conveniently downloaded via an app, either in the home where the alarm is installed or remotely. This protects occupants, assists with servicing requirements, supports those in supported living, and can provide detailed information for research and analysis purposes. However, at present smart alarms are at the higher end of the market and currently are not yet common place.

Some CO alarms (dependent on quality) can also be sent back to the manufacturer and analysed for information. First responders may be unlikely take CO alarms as evidence from an incident, hence this could be a missed opportunity to gain valuable data. It is noted that even the best alarms may not be correctly positioned in rooms, so readings can be incorrect. If practicable, the position of the alarm could be noted, perhaps via photograph.

Q3 How can CO data practices be improved?

- **Consistency:** what is recorded by whom, when. A national protocol for first responders
- **Integration:** linking the chain of records for an incident (e.g. FRS with NHS with GDN)
- **Centralisation:** alignment of records via reporting
- **Education** of those capturing data and supporting survivors to ensure that CO exposure is accurately recognised and effectively responded to
- **Increasing** the sources where data is collected

Data Collection - challenges

There is no set protocol for attending or responding to a CO incident. First responders may be from the Fire and Rescue Service (FRS), the police, the gas emergency service or another body; and data collection practices within these services vary widely.

While waiting for assistance at a CO incident, the correct action for a member of the public to take is to ventilate the area. However this means that when the FRS or other first responder arrives there is very little residual CO in the area and it is impossible for a representative atmospheric reading to be taken. Therefore we must avoid thinking that atmospheric readings are the solution to better CO incident data. It would be useful to know exactly what information the four GDNs currently record and if this there is any possibility that this might be reviewed and aligned. When combining data from different sources, duplication of records is a potential issue.

Ideas:

Workshop attendees raised that there is data policy for the emergency services, and each year there is discussion about what fields of information should be included in this. For data collection to be effective, decisions about what to record need to be implemented on a national rather than local level.

A template or questionnaire for first responders with essential categories of information to record and questions to be asked at the time of attending the CO incident could be developed to support consistency. It is noted that information is more freely given by those affected by CO when requested at the time of the incident rather than in follow up; so having access to a prepared questionnaire at the scene may increase the amount of data collected as well.

In order to enable local services to adapt to the needs of their community, it may be advantageous to consider 'circles' of data, where the first circle includes the absolutely vital information that all services must record and report. The second 'circle' would provide an opportunity for local bodies to include wider data for their own analysis and purposes. Keeping the first circle as simple as possible with just the refined categories of essential data would avoid potential error and complication.

A helpline for CO survivors could assist with data collection, as the individual could be given advice and signposted to the correct agencies and services. The survivor would then become the link between their own records. If this was implemented on a national basis, the helpline itself would collect a wealth of data on CO incidents based on information provided by survivors.

As well as set factors/fields of data to be recorded, it is important to consider the coding of that data as well. Using standard definitions means that data can be mined by Artificial Intelligence (AI) which is essential when working with large data sets that cannot feasibly be analysed by humans. When bringing together data from different sources, a holistic approach is required. There are significant hurdles in comparing and collating data from disparate sources if it is not recorded in a uniform manner. Agreeing set categories of data and standard definitions means that data can be combined smoothly and generate accurate predictions.

Members of the public are familiar with household surveys, some of which are run locally and some nationally. There may be potential for a question(s) on gas appliances (or similar) to be included in these existing data collections, which could then be accessed as open source data.

Attendees:

Baroness Finlay, Co-Chair APPCOG
John McNally MP, APPCOG Parliamentary Officer
Chris Bielby, Chair of the APPCOG's Stakeholder Forum
Dr Issie Myers, Chair of the APPCOG's COMed working group
Rob Lyon, Chair of the APPCOG's Comms working group
David Goodall, Chair of the APPCOG's Sci-Tech working group
Dr Gill Jackson, National Poisons Information Service
Steve Dacre, Northern Gas Networks
Mark Hazelton, Gas Safety Trust
Adrian McConnell, Gas Safety Trust
Hayley Tranter, Cadent
Phil Burrows, Cadent
Dan Edwards, SGN
Kerry Potter, SGN
Ian McCluskey, IGEM
Scott Darroch, Gas Safe Register
Dr Steve White, Cromwell Hospital
Dr Julie Connolly, Liverpool John Moores University
Pieter Bothma, James Paget University Hospitals

David Knipe, OFTEC
Chris Morris, Newcastle University
Phil Cleaver, Chimney Skills Training
Avril Samuel, Katie Haines Memorial Trust
Gordon Samuel, Katie Haines Memorial Trust
Robert Flanagan, Kings College Hospital
Rebecca Close, Public Health England
Ian McCluskey, IGEM
Hilary Wareing, Improving Performance In Practice (IPIP)
Dr David Wood, Guy's and St Thomas' NHS Foundation Trust
John O'Grady, Comms Group member
Jilly Robson, London Fire Brigade
Gaia Alexander, London Fire Brigade
Alex Ricketts, University of Sheffield
Daniela Gentile, National Poisons Information Service
Stephanie Trotter, CO-Gas Safety
Sue Westwood, CO-Gas Safety
Claire O'Meara, Fire Angel
Prof James Hanlon, Institute of Occupational Medicine
Prof Andy Shaw, Liverpool John Moores University
Hilary Bath, Think CO
Simon Main, Think CO
Maureen Nolan, Gas Safe Charity
Oona Muirhead, Policy Connect
Laura Fatah, Policy Connect

Apologies

Barry Sheerman MP, Co-Chair APPCOG
John McNally MP, APPCOG Parliamentary Officer
Luke Pollard MP, APPCOG Parliamentary Officer
Rt. Hon Maria Miller MP, APPCOG Parliamentary Officer
Elizabeth Warwick, Wales & West Utilities
Nigel Winnan, Wales & West Utilities
Alan Young, HETAS
Luke Bennetto, University of Bristol
David Wood, Clinical Toxicology Department, St Thomas' Hospital
Chris Yates, CORGI
Mari Herigstad, University of Sheffield

Expert Speaker Bios

Steve Dacre started his career as an apprentice Gas Service Engineer thirty years ago, and has progressed through the ranks to become Vulnerability Innovations Lead for Northern Gas Network. By engaging with businesses both in and out of the sector, he has built a strong understanding of the current and potential issues faced by customers and wider stakeholders, and how these might be overcome. Steve closely follows the development of technological, digital and data innovations which will bring benefit to all customers, stakeholders, employees, and the business. Steve says “My thoughts are firmly on the line of ‘If it can be imagined, it can be done!’. By keeping data at the heart of decision making, we are driving business performance forward to new horizons as we continually learn the ‘Art of the Possible’.”

Dr Gillian Jackson has a PhD in neuropharmacology and has worked for the UK National Poisons Information Service (NPIS) since 2007. Gill has a lead role in the development and distribution of [TOXBASE](#), the UK’s primary poison information database. TOXBASE is the first point of reference for all healthcare professionals treating poisoned patients in the UK, supported by a 24/7 national helpline which provides specialist advice to healthcare professionals. Gill is interested in utilising UK healthcare data to address public health concerns and provide the best possible NHS healthcare services; promoting the role that TOXBASE and the NPIS play in public health; and improving poisons information provision in under-developed countries (via the use of TOXBASE).

Mark Hazelton has served as Trustee for the Gas Safety Trust since March 2019. Mark is an expert in reducing risk and is an active Trustee, representing the trust at the National Fire Chief’s Council and Home Safety Committee. Prior to becoming a trustee Mark served in the Fire & Rescue Service (FRS) with Kent Fire Brigade and London Fire Brigade (LFB), for a total of 30 years. He served in various ranks including as an operational Deputy Assistant Commissioner in the LFB. During his service he served in a wide range of positions that included the Channel Tunnel fire station, fire safety regulation, training, operations and community safety. He represented the FRS nationally as lead for Chemical, Biological, Radioactive and Nuclear personal protective equipment, Carbon Monoxide Safety, and Smoking Fire Reduction.

Appendix 1

The steps to taken by the NPIS for compliance with legal obligations for data sharing:

Firstly establishing the legal basis for holding the data, e.g. legitimate business interests as in the case of SGN. Then establishing the legal bases for using the data, which is ‘for reasons of public interest in the area of public health’.

Secondly, handling of data must be set out: a Data Protection Impact Assessment (DIPA), IT Security Assessment and data sharing agreement between SGN and NHS Lothian were completed.

The final consideration is whether the individual (i.e. consumer or patient) would expect their data to be used in such a way. The Public Benefit and Privacy Panel will decide this.

Secretariat Contact

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