Public Health England

Surveillance of BPSU Rare Childhood Disease

Surveillance of Elevated Blood Lead in Children (SLiC)

A British Paediatric Surveillance Unit analysis

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Executive summary

This document reports on the outcome of a British Paediatric Surveillance Unit (BPSU) Study of Clinically Recognised Elevated Lead Concentrations in Children in the UK and Ireland (SLiC). This work was commissioned by Public Health England and was undertaken in collaboration with UK devolved administrations in Northern Ireland, Scotland and Wales and the Health Service Executive in the Republic of Ireland (RoI).

The study has employed the British Paediatric Surveillance Unit (BPSU) methods to obtain case notifications of newly recognised cases of children aged up to 16 years with blood lead concentrations (BLC) ≥ 10µg/dL (0.48 µmol/L) from paediatricians on a regular basis. Parallel reporting from Supra-Regional Assay Service Trace Elements Laboratories has been established to identify cases that may not be under the care of a paediatrician, and thus not within the BPSU orange card system.

This study considered only those cases presenting to a clinician. Many children with raised blood lead concentrations have no symptoms, or non-specific symptoms, and may not present to clinicians.

This surveillance study has collected data on 46 confirmed cases of children with raised blood lead concentrations across the UK and the Republic of Ireland over the 24 month period of the study (2010-12). Although more cases were reported than in previous years through statutory public health notifications and laboratory reporting, this is still a likely underestimate of the numbers of children affected.

Although uncommon, raised blood lead concentration can have a significant health impact and is preventable. Most cases were reported via laboratories. This offers the best scope for robust future identification and reporting of lead cases.

Most of these children are reported to have pica[1], which was thought to be the underlying reason for exposure to lead containing compounds. Paint was the most common suggested source of lead identified, with soil second.

Limitations of the study were that identification of the source of exposure relied on clinical reporting. The study did not request the results of environmental testing for lead. Environmental testing may not have been carried out in all cases, for example

[1] An eating disorder characterised by the persistent ingestion of non-nutritive substances at an age where this is developmentally inappropriate.

testing for lead in paint, toys and soil. However, these findings are consistent with risks identified in research studies and screening or hazard assessment in other countries. This study has informed the development of guidance and training material for public health practitioners, paediatricians and environmental health teams investigating incidents involving exposure to lead.

Paediatricians, general practitioners and other clinicians have a role in the advocacy for their patients and families, and in working with public health and environmental health organisations on prevention and mitigation of lead exposures. Responses showed that many clinicians are not aware of the role of Public Health Organisations (PHOs) for non-infectious environmental hazards, for example in confirming the source of exposure using environmental testing, or how to contact them.

Recommendations

The following recommendations address prevention of lead exposure in children and investigation and reduction of exposure where this has already occurred. This will require collaboration across healthcare,environmental and public health agencies, and will be guided by increasing evidence on the burden of lead, sources of exposure and feasibility of interventions.

Recommendation 1: Continue laboratory based lead surveillance and develop other approaches to surveillance.

In England this could be included as part of the Public Health England's (PHE's) Environmental Public Health Tracking (EPHT) and Environmental Public Health Surveillance System (EPHSS). The devolved nations are also using and exploring different approaches to surveillance. After the SLiC study data collection was completed, PHE piloted a laboratory surveillance system, and this has now been formally evaluated (1)

Recommendation 2: Build and strengthen relationships between public health, paediatrics and other related clinical specialties to improve reporting of children with raised blood lead concentrations, and provide a more timely public health response.

It is recommended that all cases of childhood elevated blood lead concentrations be referred to Public Health Organisations (PHOs), even if the source of exposure appears obvious, in order that remediation for the case and other vulnerable children can take place.

Recommendation 3: Review the need for targeted screening to identify children at high-risk of lead toxicity, as many children with raised blood lead concentrations do not have symptoms.

Recommendation 4: Update the advice and guidance for the public, healthcare and environmental health professionals on lead hazards and risks, and prevention or mitigation of environmental exposures.

Recommendation 5: Review the evidence for making homes in the UK and the Republic of Ireland (RoI) 'lead safe', for example by removing sources of lead in homes and preventing exposure, particularly in at-risk groups.

Recommendation 6: Update advice for environmental health officers on environmental investigation and control measures, so that local authority response is appropriate and consistent.

Recommendation 7: Update advice and guidance for paediatricians, general practitioners, and other clinicians on the diagnosis, investigation and clinical management of raised blood concentrations.

Recommendation 8: Consider analysis of the costs of investigation and management of raised blood levels in children in the UK and the RoI, and the potential costs and benefits of prevention, in order to provide evidence for the most cost-effective strategy.

Acknowledgement

This report is the outcome of a PHE study undertaken in collaboration with the British Paediatric Surveillance Unit (BPSU), the Department for Environment, Food and Rural Affairs (Defra), UK devolved administrations, Health Service Executive Republic of Ireland, National Poisons Information Service (NPIS) and the Supra-Regional Assay Service (SAS).

PHE acknowledges the role of the BPSU in facilitating the data collection. BPSU is a partnership between the Royal College of Paediatrics and Child Health, PHE and UCL Great Ormond Street Institute of Child Health, which receives additional funding support from Great Ormond Street Hospital Children's Charity. PHE also thanks the reporting clinicians, particularly those who completed the questionnaires. Any views expressed (in publications) are those of the investigator and not necessarily those of the funding bodies.

Introduction

Lead continues to be an important and probably underestimated cause of morbidity and mortality. The World Health Organization (WHO) estimates that exposure to lead accounts for 63.8% of the global burden of idiopathic intellectual disability (2), 3% of the global burden of ischaemic heart disease and 3.1% of the global burden of stroke (2).

In the UK and Republic of Ireland, policy actions have reduced environmental lead concentrations considerably but there is limited evidence on the current population exposure distribution. However, cases of lead toxicity do occur, particularly in children, and obstacles are often encountered in the effective and timely management of these cases (3). Furthermore, national surveillance data from the United States (US) indicates that while blood lead concentrations in children have decreased significantly over the last decades, a proportion of children continue to have harmful levels of exposure(4).

Individuals who are identified clinically, with signs and symptoms of lead toxicity, represent the small minority at the upper levels of exposure.

Epidemiological studies involving large numbers of children from diverse socio-economic and ethnic groups indicate that blood le ad concentrations below 10 µg/dL (0.48 µmol/L) are associated with IQ deficit (5) poorer academic attainment (6) and a range of behavioural problems, including criminality in later life (7). Most children with exposures at this level are unlikely to be identified clinically, as they may be asymptomatic or have non-specific symptoms (8).

It is reasonable to assume that a proportion of children in the UK have blood lead concentrations that are ≥10 µg/dL (0.48 µmol/L), given the UK's history of industrialisation and the age of the housing stock.

This study aims to begin to meet the deficit in existing knowledge surrounding the population exposure distribution of lead in children living in the UK and RoI. Developing a better understanding of the current situation in the UK with regards to children who are diagnosed with lead toxicity, common sources of exposure and barriers to effective management is essential in order to optimise and enhance the public health response.

Aims and objectives

The study had an overarching aim of building capacity within PHE to investigate environmental public health hazards. This included developing institutional experience of how the British Paediatric Surveillance Unit (BPSU) active surveillance methods could be used to investigate environmental public health hazards (9).

The project was a pilot for developing a system of parallel reporting from the laboratories and clinical toxicologists, and other clinicians. The equivalent relationships and reporting mechanisms are well-established, formalised and largely automated for infectious diseases (10).

Aims

Desired outcomes of the SLiC study were:

- to report the incidence of clinically diagnosed blood lead concentrations ≥10 µg/dL (0.48 µmol/L) in children in the UK and Republic of Ireland, including distribution by sex, age, ethnicity and clinical presentation in 2010-2012
- to describe the management and short-term outcomes at one year after diagnosis of elevated blood lead concentrations (≥10µg/dL 0.48 µmol/L)
- to report the proportion of cases in whom a source of exposure was identified and to describe the main sources of exposure to lead in these children
- to raise awareness among paediatricians about the clinical presentation and management of lead exposure in children, including the involvement of clinical toxicologists, public health and environmental health professionals in contact tracing and exposure remediation
- to develop a methodology for routine surveillance of potentially environmentally related diseases and tools for hypotheses generation on the relationship between environmental hazards and health
- to identify interventions for reducing children's exposure to environmental lead in the UK

Objectives

Objectives were to:

- develop a database for recording health outcomes and environmental exposure information, for use in health surveillance
- develop surveillance tools to gather information on elevated blood lead concentrations in children and link this to National Poisons Information Service and Supra-Regional Assay Laboratory data

- establish a network for the various professional groups involved in responding to environmental lead exposure in children, and to establish processes and structures for these groups to exchange information; thus providing the basis for the investigation of other environmental public health hazards
- formalise information exchange processes between the laboratories, clinical toxicologists and public health
- provide institutional experience of the BPSU surveillance system within the Health Protection Agency (HPA, now PHE) Centre for Radiation, Chemical and Environmental Hazards (CRCE) in order to facilitate its adoption in future investigations, including those involved in acute incidents
- undertake a public consultation to determine ways of increasing awareness amongst the public of sources of lead and promote remediation measures.
- improve the investigation of environmental sources of lead by promoting awareness amongst public health professionals
- support the development of evidence based guidance for environmental health teams investigating possible incidents involving lead exposure in children
- promote awareness amongst paediatricians of the role played by their local Health Protection Team in incidents involving lead exposure in children

Background

Exposure to lead in children

Lead is a ubiquitous environmental pollutant. Despite major public health interventions in the UK and other developed countries, there remains a range of sources through which children may become exposed. These include: old indoor paint; outdoor paint; drinking water contaminated mainly by consumers' lead pipes; ingestion and inhalation of contaminated soil and/or dust; and some traditional medicines and cosmetics, such as contaminated kohl (11).

In pre-1970's housing stock, lead paint may be present and if this cracks, peels or is exposed during house maintenance/renovation, particles can fall onto hard and soft surfaces. Children can inhale the contaminated dust or ingest lead particles through normal hand-to-mouth behaviour or pica.

Young children are particularly vulnerable to the effects of lead exposure due to the sensitivity of the developing central nervous system to neurotoxins. Children absorb 4-5 times more lead than adults and are also likely to experience higher levels of exposure to lead due to the time they spend on the floor in their early years and normal hand-to-mouth behaviour (11).

Epidemiology of lead exposure and related health effects in children

Lead is a cumulative toxin that can affect the neurological, cardiovascular, gastrointestinal, haematological, musculoskeletal, ocular, renal and reproductive systems. At higher levels of exposure, signs and symptoms include peripheral neuropathy, anaemia and encephalopathy (12). There is a robust body of evidence indicating that there is no safe threshold for exposure to lead and that harm occurs at levels considerably lower than those at which clinical signs and symptoms become apparent (5,13).

Some children have blood lead concentrations that are high enough for overt signs and symptoms of toxicity to develop, with the subsequent involvement of health professionals in their care; however, these children are in the minority. Signs and symptoms at lower levels of exposure are less well-characterised, are likely to be non-specific and may be sub-clinical, potentially resulting in delayed diagnosis and treatment.

Consequently, the World Health Organization (WHO) now adopts a threshold of 5 µg/dL as the blood concentration at which harm occurs for the WHO national and global

burden of disease assessment methods (14). The US Centers for Disease Control and Prevention (CDC) Advisory Committee on Childhood Lead Poisoning Prevention (ACCLPP) in the US has also recommended the term “blood lead level of concern” is no longer used in the policy context (15). The CDC has also adopted a reference blood lead concentration value of ≥5 µg/dL based on the 97.5th percentile of the National Health and Nutrition Examination Survey (NHANES) blood level distribution in children (16).

The project team recognises the evidence indicating that there is no safe threshold of exposure to lead; the case definition for this study was based on a pragmatic threshold of blood lead concentration ≥10 µg/dL (0.48 µmol/L) as this was the value at which public health action was recommended at the time the project was conceived. It was also a pragmatic decision based on laboratory capabilities across the UK and Devolved Administrations [2] (DAs) at the time of the study to measure blood lead concentrations below 10 µg/dL (0.48 µmol/L).

Epidemiological evidence

At the time of the study, there was limited evidence on the incidence of clinically significant lead toxicity and no formal monitoring of childhood blood lead concentrations within laboratory or clinical systems in the UK and RoI. There remains limited evidence on the prevalence of elevated blood lead concentrations in children. In 2013, the UK National Screening Committee reviewed the evidence in support of universal screening of blood lead concentrations in children aged 1-5 years in the UK and recommended that it should not be adopted in the UK (17).

The Avon Longitudinal Study of Pregnancy and Childhood (ALSPAC) in 1995 (18) measured blood lead concentrations in 585 children, revealing a mean of 3.44 µg/dL at 2.5 years of age. While the mean blood lead concentration was relatively low, it is notable that 5.4% of the children had a blood lead concentration >10 µg/dL (0.48 µmol/L). Data from the ALSPAC cohort follow up has shown that, after adjusting for confounders, higher blood lead concentrations were associated with antisocial behaviour, and lower reading, writing and spelling grades on Standard Assessment Tests (SATs) at 7-8 years of age (19). These findings were statistically significant. The authors conclude that exposure to lead in early childhood has an impact on subsequent educational attainment, even at blood lead concentrations <10 µg/dL (0.48 µmol/L). They suggest that blood lead concentrations should be measured in all children presenting with behavioural or educational difficulties.

[2] Wales is currently using a lab based system for under 6 year olds that reports at ≥5µg/dL

In 2001, a case control study of children in the UK with developmental and behavioural problems found that children with behavioural and/or developmental problems were more likely to have higher blood lead concentrations than controls; the association was particularly apparent for children with blood lead concentrations >10 µg/dL (0.48 µmol/L) (12% (cases), 0.7% (controls); p<0.001 (20).

US biomonitoring data has identified that children living in families below the poverty level and children living in older housing have statistically significant higher blood lead levels (21). The potential link between elevated blood lead concentrations and socio-economic deprivation in the UK has not previously been explored due to a lack of epidemiological data.

Societal impacts and costs

Exposure to lead is a cause of avoidable morbidity, hospital admissions and irreversible cognitive impairment with a consequent impact on individuals, family and society. While removal from exposure is all that is needed in most cases, rarely chelation therapy may be required (22).

Population-level action has been advocated to minimise childhood disability, and control of exposure to lead is one of the key interventions which has been highlighted (23). Cost benefit analyses in the US have estimated that every $1 spent on primary prevention through reducing lead hazards in housing would produce between $17 and $221 in benefits by reducing costs of screening and managing cases of lead toxicity (24).

Study design

This was an active surveillance study of incident laboratory-confirmed cases of elevated blood lead concentrations (BLCs) first diagnosed between June 2010 and June 2012 in the UK and ROI.

Case definition

Any child, aged <16 years of age at the time of diagnosis, with a blood lead concentration reported by the laboratory as ≥10 µg/dL (0.48 µmol/L), with or without any of the accepted clinical signs and symptoms of lead toxicity, diagnosed between 01 June 2010 – 31 May 2012 inclusive, in the UK and ROI.

Data sources and reporting processes

Data were gathered from the following three sources, although processes were not identical across all parts of the UK and RoI (Table 1):

- BPSU clinicians via the 'orange card' reporting system
- laboratories
- public health organisations (PHO)

The PHOs involved in the project were:

- England: Health Protection Agency (HPA), now Public Health England (PHE)
- Wales: Public Health Wales (PHW)
- Scotland: Health Protection Scotland (HPS)
- Northern Ireland: Public Health Agency for Northern Ireland (PHA)
- Republic of Ireland: Health Service Executive (HSE)

Information from these three reporting streams was combined into a single record for each child. Subsequent analyses were done on the single child record.

Table 1: Reporting country and data source

Country	Reporting streams		
	BPSU clinicians Orange card	Laboratories	PHOs
England	Yes	Yes	Yes
Wales	Yes	Yes*	Yes
Scotland	Yes	Yes	No
Northern Ireland	Yes	No	Yes
RoI	Yes	Yes*	Yes
*labs requested to send details of any possible cases to their PHO			

All paediatricians in England, Wales, Scotland, Northern Ireland and the Republic of Ireland (RoI) who were members of the BPSU completed a monthly orange card, indicating whether they had seen a child who fitted the case definition during the previous month. When a case was positively notified via the orange card system, the BPSU assigned a unique BPSU number to that report and provided contact details for the reporting clinician to the PHE project team. Figure 1 outlines the process involved.

Clinicians reporting a case through the orange card system then received a Case Notification Form (CNF) for completion from the PHE team running the SLiC project (a copy is included in the online supporting documentation associated with this report). The accompanying covering letter suggested that the paediatrician inform their local PHO for support. Contact details for the relevant local teams were included. The CNF requested demographic details for the case, details of their clinical management, identification of suspected source(s) of exposure, and details of other household members who may have been exposed. Additionally, 12 months after the initial notification, clinicians received a Follow-up Form (FUF) requesting details on short-term health outcomes, whether a source of exposure had been identified, and remediation measures taken, if any (for FUF, see the online supporting documentation associated with this report). All data were entered onto the database and securely stored.

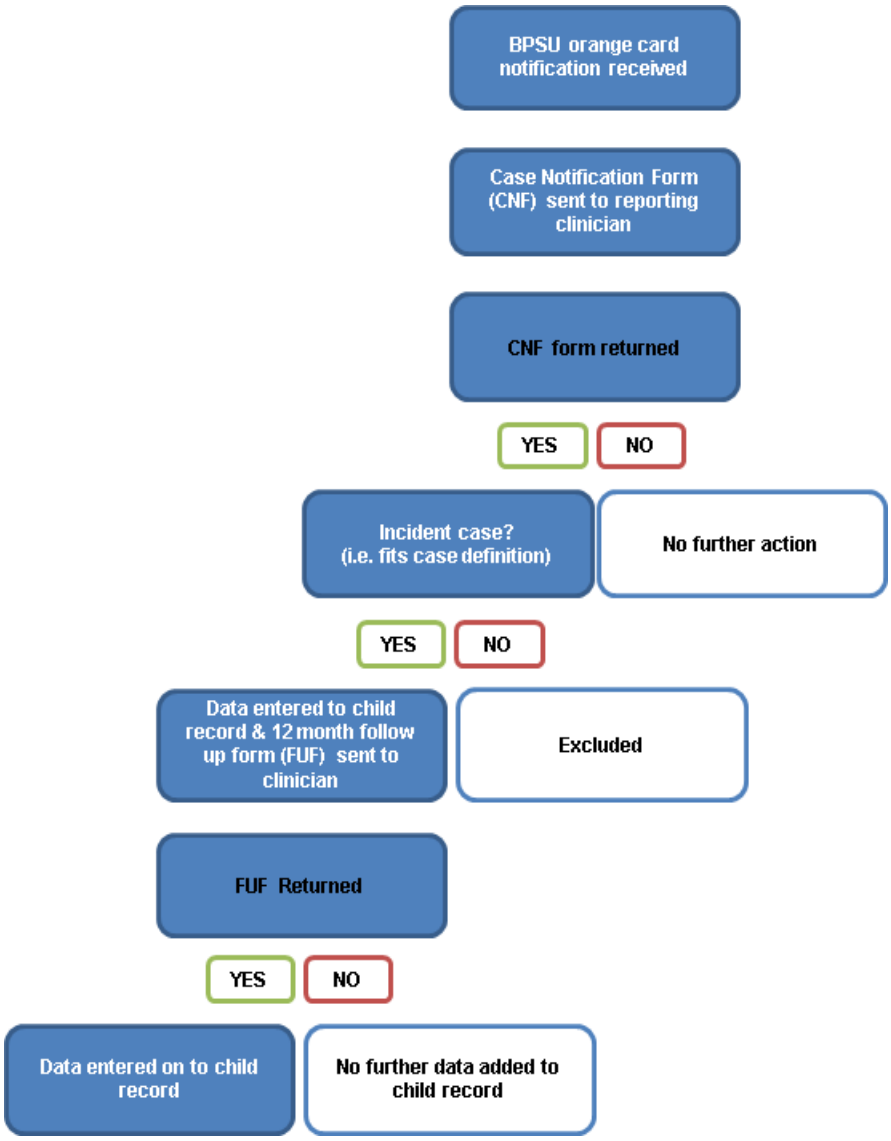

Figure 1: Reporting process for notifications via the BPSU orange card system

Laboratory reporting

Parallel reporting from the laboratories was used to identify possible cases in England, Scotland, Wales and RoI (Table 1). Figure 2 shows the laboratory reporting process. In England and Scotland laboratory reporting was via the Supra-Regional Assay Service (SAS) Trace Elements laboratories. Due to complexities in setting up the reporting system, all samples for children <16 years with a blood lead concentration of ≥10 µg/dL (0.48 µmol/L) were reported retrospectively via data extractions covering the previous 6 months. Laboratory reports covering the two years of the study were retrieved.

Each SAS laboratory sample result reported to SLiC was given a unique laboratory number. These data were reviewed to identify where multiple samples related to the same child and/or to check for duplicates. Where multiple sample results for the same child were identified, the sample with the earliest date of receipt was used for the

primary child record. Sequential samples relating to the same child were common, as monitoring of blood lead concentrations is an important aspect of clinical management. Some duplicate reporting was also noted.

For each possible case reported via the laboratories, the project team contacted the requesting clinician and requested information regarding the possible case, in line with the process outlined in Figure 2. Information from the laboratory reports was compared with the BPSU orange card and PHO reports to identify cases which had already been reported via another route using patient date of birth, initials and clinician details. Where a CNF had already been completed via another reporting route, all the laboratory records related to that case were linked to the primary BPSU record. For new cases, a new child record was set up and the laboratory report linked to that record.

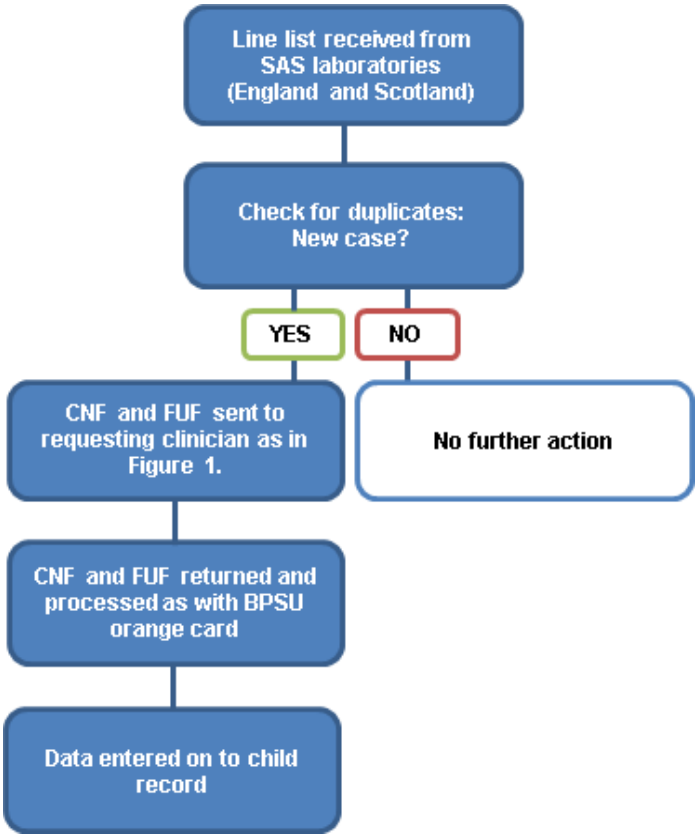

Figure 2: Laboratory reporting stream (in England and Scotland)

Parallel reporting in the Devolved Administrations and ROI

A formal arrangement with biochemistry laboratories was established in Scotland for the SLiC project but no parallel reporting was carried out in Northern Ireland. Formal parallel reporting systems were not established in Wales or RoI but laboratories were asked to report any cases to their PHO, for example the Public Analyst laboratories and University College Galway laboratory.

Public health organisations (PHO) reporting

Early in the study, it became apparent that some cases were not being referred to or treated by paediatricians; so, they would not be notified via the BPSU orange card. Therefore, as a third data source, health protection teams (HPT's) in PHOs in each country were also invited to report cases. Ethical approval for this additional reporting stream was obtained for England, Wales, Northern Ireland and Republic of Ireland.

PHOs assume a coordinating role for the public health actions, ensuring that necessary steps are taken to identify others potentially exposed, and identify and remediate the lead source using the "best practice" guidance PHE lead action card (25)

Cases were identified by interrogating PHO databases in England (HPZone and the Chemical Incidents Reporting Programme, CHIRP) and via public health teams in Wales, Northern Ireland and RoI. A CNF and FUF were sent to each PHO if they reported a case, irrespective of whether the case was already known via the BPSU or laboratory reporting route (see the online supporting documentation associated with this report). Upon receipt of completed documents, the information was uploaded on to the database and checked against BPSU data and laboratory data for linked cases using patient date of birth, initials and clinician details.

Where a case had not been previously reported, the PHO information was used to identify and contact the child's clinician with a CNF and FUF, where applicable. Figure 3 shows PHO reporting streams.

Single child record

The data received were reviewed and matched across all reporting streams to create a single child record (Figure 4). The single child record formed the basis of the data analyses.

As records were received from different sources, they often contained conflicting data. Where multiple records existed, the data were cleaned and consolidated into a single record. An Epidemiology Review Group (ERG) was established to develop a series of rules that were applied to all records.The ERG consisted of a consultant environmental epidemiologist, project investigator, project manager and two environmental public health scientists.

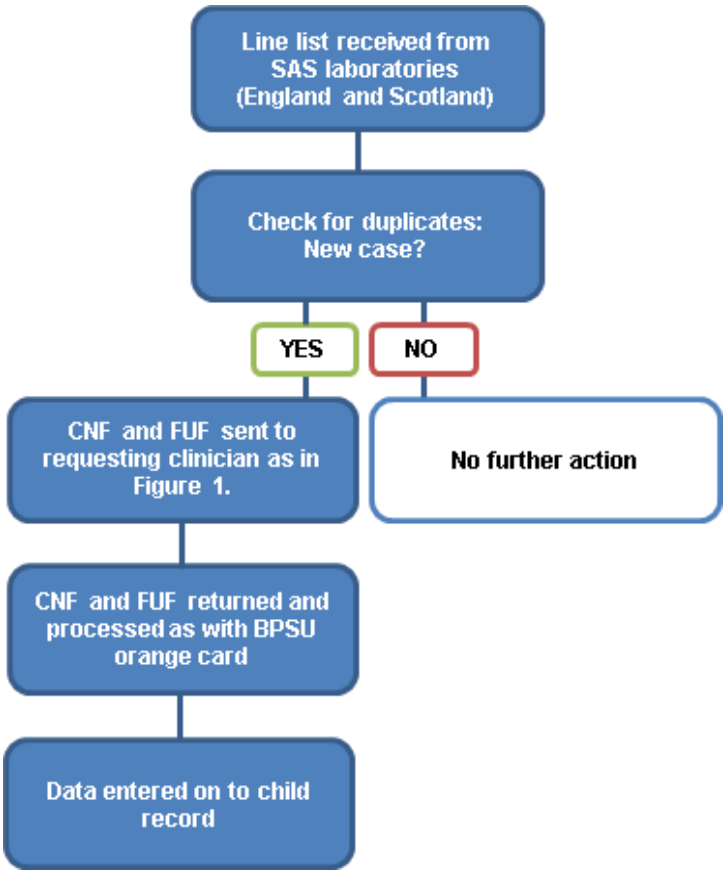

Figure 3: Public Health Organisation reporting process

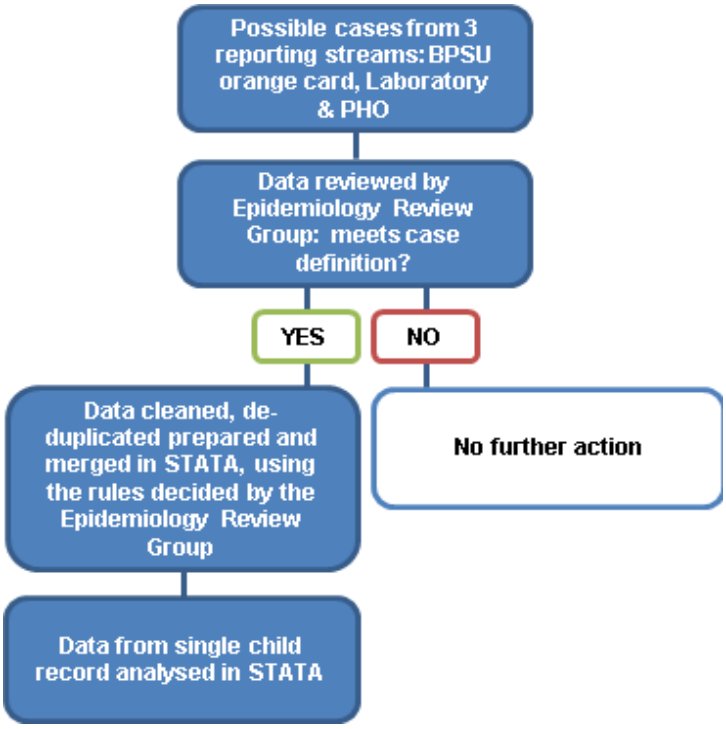

Figure 4: Creation of the single child record

Data entry, storage and security

As the datasets contained patient identifiable information. (PII) data were stored in password protected MS Excel or Access databases on a secure server, and access restricted to selected members of the SLiC ERG. Data were stored and shared according to PHE's security policy, the Data Protection Act 1998 and Caldicott guidelines.

Case matching, linking and analysis

Matching and linking was a complex process, as cases had multiple records, including:

- BPSU CNF and 12 month FUF records
- PHO CNF and 12 month FUF records
- laboratory data

Potentially linked reports were independently reviewed by the data analysis team. Other data fields such as reporting laboratory, originating hospital, clinician and date of sample were also reviewed to secure a more complete picture of reporting.

The statistical package Stata [2007] was used for cleaning and analysing the data, allowing changes to be documented and decisions revisited as necessary. To deal with conflicting data, a number of rules were developed and applied to achieve the single child record.

Where there were conflicts, or additional information (for example, in the free text fields), these were discussed by the ERG and the final case record agreed. The Stata Do files and change log contain full details of the decisions reached and changes made; a summary of the key points is available on request. The cleaned data were analysed in Stata.

Data analysis

Descriptive epidemiology

The distribution of demographic characteristics (such as age, sex and ethnicity) for cases was described; the number of cases was too small to allow for analytical statistical analyses.

Blood lead concentrations

Blood lead concentrations for each case were plotted using a histogram and box plot, and the distribution of values across the study group described.

Signs and symptoms

Following discussion with a paediatrician, an additional category for signs and symptoms which had not been included in the original CNF or FUF questionnaires was created; this category was called “neurodevelopmental issues”. This was a more generalised category, grouping several symptoms that were on the forms, including learning difficulties, plus others from free text. The rationale for this was that, clinically, neurodevelopmental issues are more likely to present as a constellation of signs and symptoms.

Socio-economic indicators and other risk factors

During the analysis phase, two different tools were used to build up home and deprivation profiles of the cases using postcode data from the single child record:

- Index of Multiple Deprivation [IMD] (26)
- dwelling age dataset (27)

These tools were used to compare the profiles of the SLiC cases to those expected in the general population, and to assess the likely level of deprivation and housing age for SLiC cases. These are important risk factors for exposure to lead, for example, the age of the housing can be a useful indicator as to whether lead-containing paint or water pipes may be present.

Where more than one case lived in the same household, the postcodes were counted separately. There were two households with multiple cases, one household with two cases and another household with three cases.

Index of Multiple Deprivation (IMD)

The IMD 2010, part of the English Indices of Deprivation, is an aggregate measure of multiple deprivation experienced by people living in an area, mapped to Lower Super Output Area (LSOA) level. IMD scores are available for England only. It is a composite score based on 38 indicators where local areas are ranked from least deprived to most deprived on seven different dimensions of deprivation:

- income
- employment
- health and disability
- education
- skills and training
- barriers to housing
- other services; crime; living environment

Each domain's contribution to the overall score is weighted differently, with income and employment deprivation weighted the most. The indicators are based on an average score of an area and cannot be assumed to represent all individuals in that area. Scores are split into quintiles, with 20% of the English population falling within each quintile. The distribution of SLiC cases across the IMD quintiles was compared to what would be expected (ie if being a SLiC case was not associated with IMD score we would expect approximately 20% of cases in each of the IMD quintiles).

Dwelling age dataset

The age of the house a case lives in is important as it is an indicator for the potential presence of lead-containing paints and pipes in the home. The dwelling age dataset can be used to provide insight into the typical age band of housing within the postcode that a case lives in; however, they do not indicate the age of the individual dwelling at the household level.

The dwelling age band has been calculated using an open source tool produced by University College London Department of Geography and The Centre for Advanced Spatial Analysis. Dwelling characteristics have been aggregated to Lower Super Output Area (LSOA) geography, and then banded by the modal age/ages across that area, using Valuation Office Agency (VOA) data. The dwelling age data is grouped in approximately ten-year age bands (plus a pre-1900 catch-all group) with a count of the number of houses in each band for each small area (LSOA) in England/Wales. The age band category assigned to a LSOA is based on the dominant age band of properties in that LSOA.

A limitation of this dataset is that it does not provide a precise age band for an individual property but gives an indication of the likely property age based on the dominant age of houses in that LSOA. The dwelling age dataset was available for English and Welsh postcodes only.

Awareness raising and professional support

During the SLiC project initiation period and throughout data capture, the project group conducted a number of reviews and training events, and produced support material for the various professional groups who were involved in responding to and managing cases of raised blood lead concentrations. As part of the analysis, representatives from Public Health Wales, PHA for Northern Ireland and the Irish HSE provided feedback on any impact from SLiC on their country (28).

Information for the public

A focus group was held in 2010 as part of the SLiC programme with the aim of exploring the public's understanding and awareness of the risks of exposure to lead, and from this to improve the information provided to the public (29).

The seven participants were all members of the HPA People's Panel living in the North East of England and all were parents or cared for children.

Internal HPA staff audit

In November 2010, an audit was undertaken by HPA (now PHE) to assess the public health response to cases with raised blood lead concentrations in 11 local PHO teams in London, Eastern and South Eastern England, and to provide a baseline for the wider activities of the SLiC project. The questions explored actions the teams took and any current gaps in training or tools. Answers were used to update tools and develop training (see below).

Lead action card for health protection

In preparation for the anticipated increase in the number of investigations of cases with raised blood lead concentrations, a lead action card aimed at public health staff was updated (25). The action card, describes how public health staff should respond to a notification of raised blood lead concentration in a child, sets out the roles and responsibilities of different organisations that may be involved in management, and provides a questionnaire for staff to complete with the child's carer to try to elicit the source of lead. The questionnaire could be administered by phone or in person on a site visit, and could be conducted by local authority or health protection staff.

Public Health Wales and the Public Health Agency for Northern Ireland have similar multi-agency procedures in place for use detailing the arrangements between public health teams, the local authority and water companies, which were strengthened as part of SLiC.

Training and workshops

Training of staff was provided in all of the countries involved in SLiC to varying degrees, according to local systems (28). In Northern Ireland, reactive PHO staff were provided with extra training on raised blood lead concentrations. In addition, informal awareness-raising was conducted with laboratories and some training was carried out with the school survey partners (schools and Education Authority) and with Northern Ireland Water. In RoI, training and awareness-raising was conducted with the local Medical Officers of Health and local paediatricians.

In England, a series of workshops were carried out by the HPA (now PHE) to both publicise SLiC and to provide training for professional groups involved in the response to cases with raised blood lead concentrations. The agenda and materials from the events were shared with the other four countries and in Wales, a similar multi-agency training event was held.

The Operational Lead Days were developed in consultation with the Chartered Institute of Environmental Health (CIEH) and aimed to raise awareness of raised blood lead concentrations in children, reducing exposure to lead, and to improve multi-agency response to these incidents. Delegates were invited from PHOs and local authority environmental health staff. A total of five workshops were held in England, although additional presentations based on the workshops were also delivered at local PHOs in England and local authority training days. The workshops consisted of a number of presentations and exercises from experts from a range of disciplines and organisations, taking the delegates through the toxicology of lead and distribution of lead-containing material in the environment, through to case and source investigation, management, remediation and legislation.

During the SLiC study period, Public Health Wales was already involved in strengthening the public health response to lead, for example the Water Health Partnership for Wales (30).

Frequently asked questions for paediatricians

A clinical toxicologist from the National Poisons Information Service developed a set of frequently asked questions for paediatricians on the clinical management of children with elevated blood lead concentrations (31). These were added to the SLiC webpage, as described below.

SLiC web page

A webpage was available for the duration of the study on the HPA website describing SLiC and the URL was provided on all SLiC correspondence. Its aims were two-fold: to raise awareness of the study among users of the website and to act as a focal point for paediatricians and other professionals who wanted to find out more about the SLiC project. The webpage included an overview of the study, its public health significance, and a ‘news updates’ section. A facility for reporting cases of raised blood lead concentrations in children was provided, with links to English health protection teams, Public Health Wales, Health Protection Scotland, the HSE (RoI), and PHA Northern Ireland.

An email address was also provided on the website and all correspondence. Most of the emails received were from paediatricians who had received the BPSU orange card and

had queries about a patient and the case definition, but study staff were also contacted by groups and members of the public with an interest in lead. Queries received ranged from public health opinion on hunting with lead shot, to advice on cases, to PHO professionals in other countries asking about UK and RoI incident management processes.

Papers, conferences, lectures

Raising awareness of not only the SLiC study but of the resources developed for a range of professionals was an important aim of SLiC, and a number of posters and presentations were delivered at conferences. Additionally, training sessions were delivered at professional meetings and papers published, as outlined below (Table 2):

Table 2: Dissemination activities

Type	Title	Place & date	Audience	Authors
Article	British Paediatric Surveillance Unit (BPSU) study on elevated blood lead concentrations in children	*Chemical Hazards and Poisons Report*, September 2009	Public health, environmental health	SLiC project group
Presentation	Lead Poisoning in Children - Surveillance and Response	Northwick Park Hospital, September 2010	Hospital clinicians and paediatricians	Yimmy Chow
Article	Supporting the response to cases of lead poisoning	*Chemical Hazards and Poisons Report*, October 2010		Bethan Davies, Catherine Keshishian, Ruth Ruggles
Article	Study on elevated blood lead levels in children: Report from a public focus group	*Chemical Hazards and Poisons Report*, October 2010	Public health, environmental health	Edward Wynne-Evans, Iain Mallett
Article	The global lead challenge	*Chemical Hazards and Poisons Report*, October 2010	Public health, environmental health	Eirian Thomas, Joanna Tempowski and Lidia Martin-Couce (WHO)
Poster	Investigating lead poisoning	Health Protection Conference, September 2011	Public health, environmental health	Catherine Keshishian, Bethan Davies, Andrew Tristem, Eirian Thomas, Margot Nicholls, Ruth Ruggles
Presentation	A SLiC response to lead and health	Health Protection Conference, September 2011	Public health, child health	Ruth Ruggles on behalf of SLiC project group

Presentation	Lead in Residential Homes in London: A Potential Risk to Child Health and the Role of Public Health	International Conference on Environment & Health SEGH 2011	Academia, environmental health	Sohel Saikat, Robie Kamanyire, Catherine Keshishian
Journal	Lead and children: An old problem for young people	*British Journal of School Nursing*, February 2012	School nurses	Catherine Keshishian, Eirian Thomas, Ruth Ruggles
Poster	A SLiC response to lead and health	International Society for Environmental Epidemiology conference, August 2013	Environmental epidemiologists	Ruth Ruggles, Catherine Keshishian, Raquel Duarte-Davidson, Rebecca Close, Eirian Thomas, Sally Bradberry, Emer O'Connell, Rachel Knowles, Virginia Murray, Giovanni Leonardi
Presentation	Lead – new perspectives on an old foe	London Health Protection and Environmental Health Joint Public Health seminar, February 2013	Public health, environmental health	Emer O'Connell on behalf of the SLiC study group
Presentation	SLiC results	BPSU annual conference, April 2016	Paediatricians	Ruth Ruggles, on behalf of the SLiC study group

Results

Sources of case reporting

A total of 46 unique cases of raised blood lead concentrations in children <16 years of age were reported over the two year study period.

Figure 5 summarises the number of initial case reports from each source. Fifty-eight reports were received from paediatricians via the BPSU orange card, 24 reports were received from PHOs, and 93 reports were received from laboratories.

The case reports and laboratory reports received related to 112 children. Of these, 66 were excluded because they were duplicates, did not match the case definition, or there was not enough information available to decide if they did.

Multiple reporting routes

Some cases were reported by a single route only, whilst many were reported via multiple routes (Figure 5). 39% (18/46) of cases were reported by one reporting stream only, 41% (19/46) of cases were reported by two reporting streams and 20% (9/46) of cases were reported via all three reporting streams.

BPSU orange card

Thirty-two out of the total 46 cases were reported via the BPSU orange card of these 7 were exclusively reported via the BPSU orange card and 25 were reported by the BPSU orange card system and at least one of the other reporting streams.

Public health organisations

Nineteen of the total 46 cases were reported via a PHO (41%); 3 of these cases were exclusively reported via a PHO while 16 were reported via the PHO and at least one other reporting stream.

Laboratories

Thirty-two of the 46 cases were reported via the laboratory surveillance (70%); 8 were exclusively reported via the laboratories and 24 (were reported via the laboratories and at least one other reporting stream.

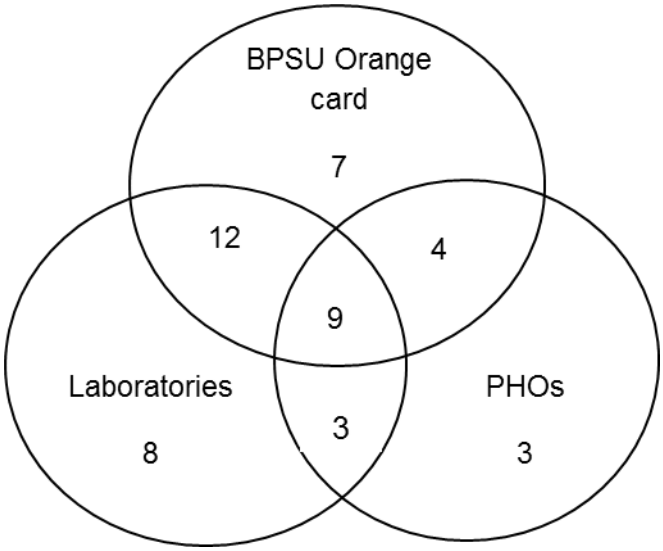

Figure 5: Case reports received via each reporting stream (n=46)

(Total cases by each route: BPSU n=32, Laboratories n=32, PHO n=19)

Case reports by country

Eighty percent of cases were reported in England (37/46).

Analysis of data from the case notification form by single child record

Demographic data

The mean age of cases was 5 years (range: 0 – 15 years). The median age was 4 years with an interquartile range of 1 – 14 years. 59 % of cases (27/46) were less than 5 years old. Approximately 62 % (28/45) of cases were male. No information on gender was available for one case. Sixty three pre cent of cases (29/46) reported White British or Irish ethnicity. Thirty three per cent (38/46) of cases were UK-born.

Index of Multiple Deprivation 2010

Eighty percent of cases (37/46) had a postcode that could be mapped using the PHE GIS software. An IMD score was assigned to 74% (34/46) of cases; the other cases were from countries other than England, did not have a postcode or had a postcode that could not be found. Table 3 provides information on the number and percentage of cases in each IMD 2010 quintile in England. The highest number and percentage of cases were in quintiles 3 and 5 (26.5% in each), and the lowest was in quintile 2 (11.8% of cases). Overall, more of the cases are in the higher, more deprived quintiles.

Table 3: Number of cases in each quintile in England, based on postcode of residence (1=least deprived, 5=most deprived)

National quintile*	IMD score range	Number of incident cases (n= 34)**	% of cases
1	<8.49	5	14.7
2	8.5-13.79	4	11.8
3	13.8 – 21.35	9	26.5
4	21.36 – 34.17	7	20.6
5	>34.18	9	26.5

* In England, expected distribution is 20% of population in each quintile
** A proxy postcode in the same street was used for two children whose postcodes were not compatible with the tool

Property age dataset

It was possible to map 67% (31/46) of cases against the property age band dataset; 45% (14/31) of these cases were found to fall within the pre-1900 housing band and 84% of cases (n=26) were living in a LSOA where the housing stock is dominated by pre-1972 dwellings.

For cases where paint was suggested as the source, the property age for the postcode was pre 1972 in most cases (88%; 15/17). For the remaining two cases, the housing age assigned to the cases' postcode area was 2000-2015.

Clinical presentation, diagnosis, paediatric referral

In two cases it was reported that there had been previous episodes of illness that might be attributed to unrecognised raised blood lead concentrations. In 52% (24/46) of cases there was not thought to be previous illness that could be attributable to raised blood lead concentrations.

Forty one percent of cases (19/46) were referred to the responding paediatrician by a GP (Table 4). Five cases were referred via both the GP and hospital. 'Other' referrals included four from a PHO who were investigated as they were in the same household or family as existing cases (two had parents with raised blood lead concentrations, and two were siblings of an affected child).

Table 4: Referral route for children seen by a reporting paediatrician

Who referred the child?	Number of cases (%)*
GP	19 (41%)
Health visitor	2 (4%)
Hospital clinician	14 (30%)
Other (including PHO)	18 (39%)
*Referrals could be by multiple routes	

Blood lead concentrations

The median blood lead concentration was 21.2 µg/dL, with a range from 10.8 to 291.7 µg/dL (Figure 6). The interquartile range was 14.5µg/dL - 33.1µg/dL. The maximum blood lead concentration was substantially higher than the next highest level which was 94.3 µg/dL, with the maximum reported blood lead concentration skewing the distribution.

Blood lead concentrations were similar in children in the 0-4 and ≥5 years age groups, and in males and females (Figures 7 and 8).

Nearly 60 per cent (58.7%; 27/46) cases were 0-4 years old; for this age group the median blood lead concentration was 21.1µg/dL (interquartile range 14.5µg/dL to 32.1µg/dL). For the ≥5 years group, the median blood lead concentration was 22.8µg/dL (interquartile range 15.3µg/dL, to 37.4µg/dL (Figure 7).

60.8% (28/45) of cases were male. One case did not have a gender reported. In males, median blood lead concentration was 20.4 µg/dL (interquartile range 15.5 µg/dL to 32.6 µg/dL. For females, the median blood lead concentration was 26.1 µg/dL (interquartile range 14.5 µg/dL to 36.4µg/dL (Figure 8).

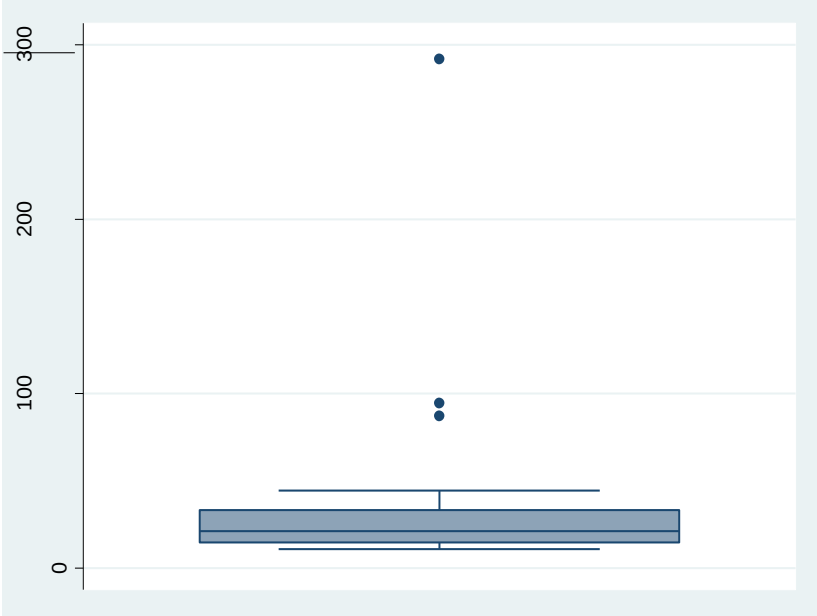

Figure 6: Box plot of index BLCs for incident cases (µg/dL)

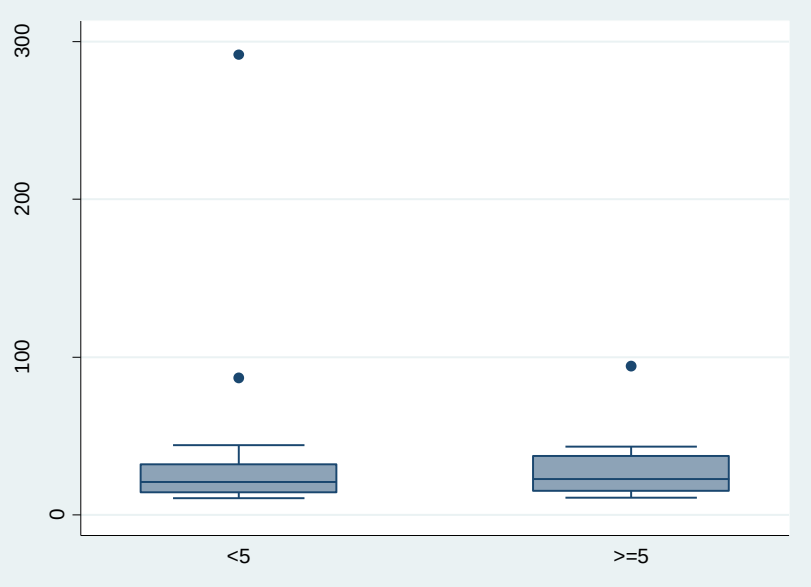

Figure 7: Box plot of blood lead concentrations for children aged 0-4 years and those aged ≥5 years (µg/dL)

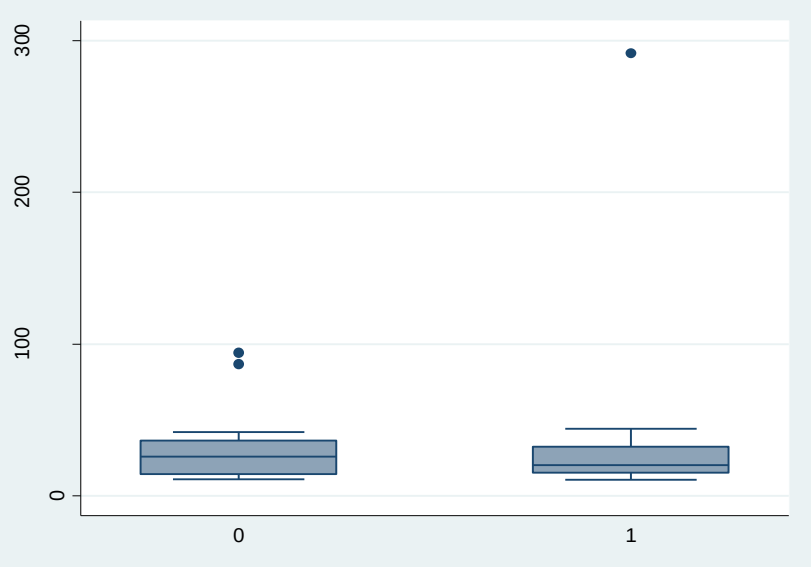

Figure 8: Box plot of blood lead concentrations by gender (0=Female, 1=Male) (µg/dL)

Reasons for blood lead testing

In 78% (36/46) of cases the reason given for testing for lead in the blood was the child's exposure history (Table 5). Pica behaviour was the reason for testing in 24 of the 46 reported cases.In 13 cases the reason for testing was screening a child with learning difficulties or development delay. In nine cases the reason given was that the child displayed clinical signs and symptoms. Nine children were tested when raised blood lead concentrations were identified in a household contact or on advice from health protection.

Table 5: Reason given for requesting the blood lead test

Reason given for the blood test*	**No. of cases**
Exposure history (including history of pica)	36 (78%) (pica = 24/36)
Screening in asymptomatic children with learning difficulties or development delay	13 (28%)
Clinical signs/symptoms	9 (20%)
Raised BLC in household contact	7 (15%)
Other	6 (13%)
Following advice: Health Protection	2 (4%)
Following advice: Environmental Health	0 (-)
*More than one reason could be given for each child	

Signs and symptoms

Fourteen cases (30%, 14/46) were reported to have no symptoms. Of those with reported symptoms, haematological symptoms were the most commonly reported (37%; 17/46), with anaemia being predominant. The next most common symptom was eating difficulties (15%; 7/46), which included decreased appetite or weight loss. A number of children were reported to have neurodevelopmental issues (35%; 16/46),although these were not necessarily casued by lead exposure. In 11 cases (24%), the free text was used by clinicians to note that the child had autism. No renal symptoms were reported.

Clinical investigations carried out

Further clinical investigations were carried out in 34 cases (74%). Twenty-nine of the 46 cases (63%) had biochemistry investigations, 28 (61%;28/46) had haematological investigations, and 4 (9%;4/46) had radiological investigations. Five (11%; 5/46) cases had other investigations undertaken, including microbiological and endocrine investigations.

Management of cases

Fifteen percent of cases (7/46) were admitted to hospital. Of the seven admissions, three were reported as having the highest blood lead concentrations(all >90 µg/dL), three children had levels of 32-43 µg/dL. One child had a blood lead concentration of 20 µg/dL but this case was admitted for a range of health problems. Nine other cases whose blood lead concentrations were >30 µg/dL, were not admitted to hospital.

The main reason for admission to hospital was for chelation therapy (Table 6). DMSA (succimer) was the most commonly used chelating agent (7%; 3/46). Other reasons given for hospital admission were: lethargy and anaemia, vitamin D therapy and dietician advice, for an underlying condition, poor feeding and suspected sepsis.

Table 6: Number of cases admitted to hospital and reason for admission

Reason for admission to hospital	No. of cases (%)*
Chelation therapy	4 (9%)
Further Investigation	2 (4%)
Iron and/or vitamin C therapy	2 (4%)
Other	3 (7%)
*more than one reason for admission could be given	

One year follow up

Twelve-month follow-up forms (FUF) were returned for 83% (38/46) of cases. Seventeen of these cases had multiple follow-up forms returned. These were combined into the single child record as described in the methods. Data were combined from the

CNF and the FUF questionnaires as well as information extracted from the free text fields.

Follow-up blood lead testing, outpatient management and hospital admissions

71% (27/38) of follow-up cases had their blood lead concentration tested in the previous 12 months, the number of times blood was taken and analysed ranged from one to nine times. Two cases had not had any follow-up blood tests, and for nine of the cases the number of blood tests was unknown. Generally, blood lead concentrations were observed to reduce over time.

39% (15/38) of cases with a 12-month follow up report had out-patient appointments, ranging from one to eight visits. Five cases had received a home visit (13%, 5/38). Home visits were from both health and social care professionals, and public and environmental health.

34% (13/38) of cases with a 12-month follow up report had been discharged from follow-up by 12 months after diagnosis. Reasons for follow up (sometimes multiple) included continued blood lead monitoring (in 13 cases), clinical conditions (in 16 cases), behavioural and developmental support (in 7 cases).
Two cases had been admitted to hospital for management of elevated blood lead concentrations within 12 months of diagnosis.

Treatment outcomes

Results below are shown for all 46 cases, although not all had follow-up information.

At the 12-month follow-up, 29 cases (63%; 29/46) were reported to be residing at home, 3 (7%; 3/46) were still in hospital, and none were reported as deceased. The whereabouts of the remaining cases (30%; 14/46) was unknown.

Exposure history

The following results are suspected environmental exposures reported by clinicians, not those from environmental analysis or investigation. Results below are shown for all 46 cases, although not all had 12-month follow-up information.

Overall, ingestion was reported as the route of exposure for 76% (35/46) of cases. In 72% (33/46) of cases pica was reported (Table 7). Three cases (7%, 3/46) were reported as exposed via their parent's work clothes or hobbies; and two children (4%, 2/46) were exposed *in utero*. No information was available for 13% (6/46) of cases.

Domestic paint was the suspected source of lead exposure most commonly cited by clinicians (52% of cases, 24/46). Water was thought to be the source in only one case (2%, 1/46). The source was unknown in 26% (12/46) of cases (Table 8).

Table 7: Number of children exposed via each pathway

Pathways of exposure*	**No of cases (%)**
Pica (ingestion)	33 (72%)
Drinking water (ingestion)	1 (2%)
Accident (ingestion)	1 (2%)
In utero	2 (2%)
Parental occupational/hobby (ingestion or inhalation)	3 (7%)
No information	6 (13%)
Total	**46 (100%)**
*Some of this information was not given in the form directly but indicated in the free text	

Table 8: Number of cases with exposure attributed to each suspected source

Suspected source of lead exposure*	**No of cases****
Domestic – paint	24
Domestic – soil	11
Domestic – drinking water	1
Domestic –cooking utensils	0
Toys	3
Batteries	3
Traditional medicines/remedies	1
'Other '(not all possible sources listed contain lead)	8 (lead weight (2), glass paint, father's clothing; plaster; moss; coal, soap; paper, crayons, pencils, cardboard)***
Unknown (includes 'pica' with no source)	12
*NB not all of these questions were asked directly, some answers were indicated in free text **Some cases had more than one source indicated. ***Not all possible sources listed contain lead	

Household contacts

Results below are shown for all 46 cases, although not all had follow-up information.

Eight (17%, 8/46) of the cases identified through the study were part of a household group. In one family group, three children were reported as eating domestic paint. The remaining five cases linked to a household group were exposed via a parent: two cases were identified as having been exposed *in utero* (mother had raised BLCs when pregnant); three of the children had a parent with raised blood lead concentrations linked to exposure via their occupation or hobby.

In addition, two children were residential pupils at the same special needs school; however there was no indication that a lead source was found at the school.

Referrals and specialist advice

Results below are shown for all 46 cases, although not all had follow-up information.

30% (14/46) of cases were referred to a clinical toxicologist, in 41% (19/46) of cases, treatment advice was received from National Poisons Information Service (NPIS). Half the cases (23/46) had been referred to the local PHO and 24 to the local environmental health team. Five children had home visits.

Public health action

Results below are shown for all 46 cases, although not all had follow-up information.

In 48% (22/46) of cases, the domestic environment was investigated; five additional cases in the study were identified as a result of these domestic investigations. Action was taken to prevent further exposure in 59% (27/46) of cases, with removal of the suspected lead source the most common action taken (30%, 14/46). See Table 9 for details.

Table 9: Action taken for suspected lead sources **Action taken**	**No. of cases (%)***
Removal of suspected lead source	14 (30%)
Moving to alternate accommodation	3 (7%)
Behavioural change advice	11 (24%)
Occupational hygiene advice	2 (4%)
Boarding over suspected source	1 (2%)
No action taken	7 (15%)
No information	12 (26%)
*More than one action could be reported for each case	

Information for the public

The seven focus group participants were all members of the HPA (now PHE) People's Panel living in the North East of England. All were parents or cared for children. The themes that emerged from the focus group data included the need for clear and accessible information on what constitutes a significant exposure, that most people would think that lead poisoning is 'a thing of the past', and that it is important that health professionals are aware of the risks of lead exposure.

The focus group recommended that materials for the public with information on lead exposure be developed. Their other recommendations included that the public should be provided with advice when buying older properties, PHOs should work with trading standards in order to run campaigns to highlight the risk to children's health of lead in toys, and that health visitors could be involved in helping to identify risks from lead exposure in the home.

Awareness raising and professional development

Feedback from PHO audit and training workshops

Ten of the eleven local PHO units approached responded to the audit, reporting involvement in a total of 27 cases with raised blood lead concentrations between January 2007 and June 2010. Sixteen of these were in children.

The audit found that in the 27 cases:

- HPA staff conducted a site visit in 37% of cases
- environmental samples were taken in 30% of cases: however, for some incidents the source was previously known.
- positive identification of a lead source was found in 26% of cases

Of all lead enquiries received (n=59), cases were far more common in London than Eastern and South-Eastern England (90% vs 50%), whereas general enquiries about environmental contamination of water or land was more common outside London.

As expected given the varied potential sources of lead, respondents reported involvement of multiple disciplines and agencies in investigation and management of cases. These included home-owners/families, clinicians, schools, public health teams, water companies, local authorities (mainly housing and environmental health teams, but also social services and health and safety), child protection agencies, Food Standards Agency and veterinary teams.

Commenting on incident management, health protection staff said:

The PHE lead action card was comprehensive and useful, although minor suggestions were made for its improvement.

Confusion over legislation and regulation in different situations, for example:

- more clarity was required on mandatory notification arrangements and the legislation available for enforcement of remediation, in particular in private properties
- clarity in the role insurance companies should play in financing remediation

The role of the Health Protection Regulations 2010 was unclear.

Feedback from the workshops was very positive, with delegates finding the multi-agency liaison and discussion particularly useful. As with the PHO audit, a number of knowledge gaps and suggestions were identified.

Local authority staff expressed limited capability to undertake environmental sampling, with finance being a significant constraint.

Cases with raised blood lead concentrations were rare, with environmental health staff investigating few, if any, through their career. An advisory service of experienced experts was thought to be useful and it was suggested that the HPA (now PHE) could be a central information point.

A ‘one stop shop’ of resources aimed at local authority staff was suggested, to include investigation, sampling and legislation advice. Further workshops that included results of SLiC and also case studies from local authority staff were proposed.

Development of suite of support materials

Following on from the above feedback, a “one-stop-shop” of resources on lead was developed for the public and professionals and added to the HPA website. This included:

- frequently asked questions for parents (32)
- frequently asked questions for paediatricians (31)
- updated Lead Action Card and questionnaire for public health (25)
- collation of resources for environmental health practitioners, including legislative options (28).

The SLiC website has now been archived. Up-to-date information for healthcare, public health and other professionals is available at the websites for the PHOs and NPIS.

Discussion

Number of cases reported

A total of 46 cases of lead toxicity in children aged <16 years old were reported over the two year study period (2010 to 2012) across the five participating countries. Although active surveillance methods were used in the SLiC study, this is a likely underestimate of the true number of children with raised BLC.

In the 12 months from April 2011 to March 2012, the UK National Poisons Information Service (NPIS) received telephone enquiries about 22 children aged less than five years old exposed to lead, and 74 reports in children aged four years and under in the period from 2008 to 2010 (32). The NPIS provides expert advice on all aspects of acute and chronic poisoning, and is the service to which frontline NHS staff turn for advice on the diagnosis, treatment and care of patients who have been, or may have been, poisoned, accidently or intentionally.

SLiC identified 27 cases in children in the same age group over the two-year period of the study. This suggests that there is a higher number of cases referred to poisons specialists in the NPIS than found through SLiC, however, it is not known whether the children reported to NPIS with lead exposures had raised BLCs.

At the more severe end of the spectrum, the number of cases reported to the SLiC study is broadly consistent with other sources of information. Seven hospital admissions were reported to SLiC. The Hospital Episode Statistics (HES) data for England in the same period (2010 - 2012) showed that there were eight admissions for the toxic effect of lead (ICD-10 code T56.0) in children aged up to 14 years old (four in 2010, four in 2011, and no admissions in 2012)(32).

Limitations of the SLiC project

The number of cases is small, with only 46 cases in total. This limits the statistical analysis conclusions. Further, not all respondents completed all questions and follow up forms were not received for some cases, resulting in missing data.

Multiple forms were received for many cases, meaning that there were some discrepancies or contradictory reports. We formed a multi-disciplinary review group and used a structured approach to resolve these, and agree the final record. A log was kept of decisions. A structured approach was applied to resolve discrepancies and rules had to be applied for missing data, and discrepancies and free text carefully examined.

For a couple of questions, answers given suggest that they were open to misinterpretation, in particular the basis on which a lead source was confirmed or suspected, whether symptoms present at time of diagnosis were related or unrelated to lead, and whether the clinical reason for ongoing follow up of a child was related to lead.

Clinicians and PHOs were asked to indicate whether a lead source was “confirmed” or “suspected”. We had assumed that responders would only mark a source as “confirmed” if it had been sampled and was shown to contain lead, and an exposure pathway had been established. The range of responses suggests that this was not always the case, and sources marked as confirmed may have had environmental testing, or may have been based on the child’s behaviours or clinical suspicion.

Deprivation and housing age were assigned based on the average for the home postcode area, rather than the individual. This could lead to misclassification of the risk factor, but this would be random and thus bias the results to null and make potential correlations less significant. Whether the suspected source reported was found in the home or elsewhere, for example at the home of another relative or carer, or at a school, is not known.

Clinically recognised cases

As with all surveillance studies, the case reports received represent only the tip of the iceberg of the clinical spectrum of children with raised blood lead concentrations living in the UK and RoI. For a child to be reported into a surveillance study requires the child to display symptoms or behaviour that prompt a parent/carer to seek medical attention, and for the clinician to consider that lead toxicity may be responsible for these symptoms or that the child has been exposed to lead. It is recognised that observable clinical signs and symptoms of raised blood lead concentrations in children, such as gastrointestinal disturbance, may not become apparent until blood lead concentrations reach around 60 µg/dL (8)**,** although less overt symptoms such as anaemia and impairment of hearing and cognition, may occur at lower concentrations of between 10 – 30 µg/dL.

The paucity of symptoms suggest it is less likely that parents/carers of children with blood lead concentrations below 60 µg/dL would actively seek medical advice. Most of the cases (87%) reported to this study had concentrations below 60 µg/dL. Although several of these cases were reported to have had signs and symptoms that may have been related to lead exposure such as vomiting and constipation, it subsequently became apparent that this question may have been subject to misinterpretation; in response to the direct question “What was the reason for blood lead testing?”, only nine clinicians (out of the total of 46 cases) stated that the case had clinical signs and symptoms suggestive of lead toxicity. There are a number of causes for gastrointestinal

symptoms and lead toxicity is unlikely to be high on the list of differential diagnoses for clinicians.

Missing information

As outlined in the methods, it was not possible to use all three reporting streams in each country. Laboratories in England and Scotland were a common source of reports (Figure 5). It is possible that cases in Northern Ireland might have been missed as the laboratory reporting stream was not established at the time of the study, but this was thought unlikely as there were established communications between laboratories and PHOs in all countries.

Forty-four percent of laboratory reports (41 of 93 laboratory reports received) were discarded because not enough information was available to decide whether or not they related to a case. For example, the laboratory report did not contain sufficient information to enable follow up, or the clinician didn't respond to follow up letters; it is probable that some of these did relate to unique cases not picked up by the BPSU or PHO reporting streams. Similarly, 45% (26/58) of reports of possible cases received via the BPSU orange card were excluded as CNF was not returned or there was not enough information to establish if the child met the case definition.

Reporting sources

Nearly all consultant paediatricians across the five countries are registered on the BPSU reporting scheme and the response rate to the monthly orange card is typically between 90% and 95% (9). It is therefore reasonable to conclude that most cases of children with raised blood lead concentrations under the care of a paediatrician were reported to the SLiC study.

There were 14 cases known to the laboratories or a PHO that were not reported via a paediatrician during the study period (Figure 5). There are a number of possible reasons for this. It is possible that some paediatricians are not registered on the BPSU orange card reporting scheme, or wait for laboratory confirmation before reporting the case and in this instance might forget to report it to the BPSU. Questionnaire returns are approximately 80% in BPSU studies (9). It was established early in the study that not all children with raised blood lead concentrations were treated by a paediatrician after a PHO professional on the SLiC project group noticed that the cases in an incident they were managing had not been reported via the BPSU; it transpired that these children were being treated by a general practitioner in the community.

Figure 5 illustrates that most reports came from paediatricians via the BPSU orange card system and the laboratories; PHOs were the least common reporting stream. None of the reporting streams reported all of the cases, so public health surveillance of raised blood lead concentrations in children should consider using more than one

complementary system, as with infectious diseases. It is hoped that the raised awareness among paediatricians to notify PHOs will be sustained as a result of SLiC in all the countries involved.

The relationships developed between laboratories and PHOs has been a lasting legacy of SLiC. A recent evaluation of a 12-month pilot of laboratory reporting, which has been run post-SLiC, identified 35 cases of children (using the SLiC case definition) in England alone indicating that this is a valuable source of information (1)

Case demographics

Age and sex

Nearly two-thirds of the cases identified in SLiC were males. In a study of targeted screening of children with learning disabilities/developmental delay based in England, all of those found to have raised blood lead concentrations were male (nine cases ≥5 µg/dL, one case ≥10 µg/dL), although 76% of their study population was male (33). A non-targeted Swedish survey of blood lead concentrations in children also shows that boys have higher mean concentrations (34) as do US population data (35). It is not clear why there are more boys; a literature review on pica, a common risk factor for raised blood lead concentration, does not show higher prevalence in boys (36).

Most cases were under the age of five (59%), an age when pica is common. A rate of 50% pica behaviour is considered normal for children 18 to 36 months, falling to about 10% for children over 12 years of age (37). Three quarters (12/16) of cases aged six years and over had pica and for most (8) of these children had a neurodevelopmental diagnosis such as autism spectrum disorder (ASD).

Ethnicity

One-third (15/44) of cases where ethnicity was reported were described as non-white or of mixed race. This compares with a non-white population of 14% in England and Wales in 2011 (38) and lower proportions in the other three countries (Scotland 4%, Northern Ireland 1.8% and RoI (39-41). It is simplistic to infer or assign behavioural characteristics to ‘white’ and ‘non-white’ populations, however, the disproportionate burden of lead toxicity in non-white ethnicities is well-evidenced in the literature (35). Established explanations for ethnic inequalities in health status include social, educational and economic status, living environment, pre- and post-migration, and culture and lifestyle (42-43).

As previously discussed, pica was the most common reported cause of raised blood lead concentrations in this study. All but one of the 15 non-white cases had pica, with this case reportedly being exposed *in utero* by the mother taking Ayurvedic medicine in India. Pica is more common and acceptable in some parts of the world, notably the

Indian sub-continent and parts of West Africa, where it can be seen as of medical or cultural benefit (44). This may result in children being less likely to be prevented from eating non-foodstuff, or parents being less likely to report this to a medical practitioner. This may also reflect greater testing for raised BLCs in children with pica.

Born outside the UK/RoI

The section of the questionnaire regarding country of birth and whether the child was born outside the UK/RoI was poorly completed. No clinician answered the question regarding the age at which the child entered the UK or the country of residence prior to entering the UK. This question was included as children and adults may have been exposed before migrating to the UK/RoI, for example, their country of origin may still use leaded petrol. Research from the US in the 1990s showed that 11.3% of 693 recently arrived refugee children had blood lead concentrations above 10 ug/dL, rising to 27% of children from Somalia and Vietnam (45). Further research showed that the BLC for many immigrant children actually *increased* after arrival in the US, which has led the CDC to recommend that all refugee children from the age of six months to 16 years are tested for lead upon entry to the US (46). It is suggested that this is because refugee children are exposed to lead hazards such as paint in poorly maintained homes, are unaware of these hazards within the US and can be malnourished; a similar picture may apply to the UK.

Socio-economic status

The results must be interpreted with caution, due to the low number of cases, and because socio-economic status was assigned based on postcode and not to individual cases.Our results suggest that there were more cases in more deprived areas. This is consistent with evidence that both pica and lead toxicity are higher in lower socioeconomic status groups (38, 50). This could be due to living in older homes in a poorer state of repair and malnutrition from diets with reduced levels of calcium, zinc and iron, which are risk factors for pica and increased absorption of lead (35, 47). Generally, for a child to access chips of leaded paint, the paintwork would have to be in poor repair.

Place of residence and geographical clustering

Although there were at least two reporting streams in each country, most cases were reported in England with only one in RoI and none in Northern Ireland. This may be due to relative population sizes and the different coverage rates of the reporting streams.

The most commonly suspected lead source overall was household paint, which (alongside lead water pipes) is associated with houses built before 1970 (50) and our results are consistent with this. Housing stock age varies widely across England and Wales, with the proportion of homes built pre-1972 ranging from 23% in Milton Keynes

to 84% in Blackpool; nationally, 66% and 68% of domestic homes in England and Wales respectively were built pre-1972 (51). London has the oldest housing stock regionally. The private rented sector has the highest proportion of houses built pre-1964 than any other housing tenure in England (43). Publicly owned housing stock in Scotland is of a similar age (60% were built pre-1965) (52), however housing in Northern Ireland is proportionately younger (38% built pre-1965) (53).

Another reason for geographical variation in reporting may be differences in rates of reporting and diagnosis, which can be due to variations in clinical practice amongst primary and secondary care practitioners and awareness of the roles of PHOs in lead incident management. Some paediatricians are more aware of the potential for raised blood lead concentrations, which could lead to higher rates of diagnosis. Anecdotally, it appears that clinicians are more likely to consider lead toxicity as a diagnosis if they have had previous experience of dealing with a case. Geographical variation could also reflect differences in reporting to PHO or toxicology units. This is an area for possible improvement and an issue which was addressed by the SLiC project.

Source and exposure pathway to lead toxicity

Clinicians were asked to indicate whether sources of lead were ‘confirmed’ or ‘suspected’. As these terms were not well-defined and information on environmental sampling results were not requested, it is not possible for us to state that any source indicated by the respondents was positively confirmed by testing.

Ingestion of paint and soil

Pica behaviour was reported for the most of children with raised blood lead concentrations. For two thirds of those with pica, domestic lead-containing paint was thought to be a source of exposure, with paint on toys accounting for a further three cases.

Up until the 1950s, UK paint used for wood and metalwork may have contained up to 50% lead by weight, which is potentially capable of causing lead toxicity in a small child if they ate just a single chip. Leaded paint at these concentrations may still be found in non-remediated Victorian properties. Voluntary agreements such as the 1968 British Standard to label paint with concentrations less than 0.5% as ‘low-lead paint’ (54), and legislation (55), have reduced the volume of lead used in paint (except specialist paints) in England, Wales and Scotland, so that houses built since 1970 are unlikely to contain this hazard. As above, around two thirds of the housing stock in England, Wales and Scotland was built before 1972 (51-52).

Consumption of soil was stated as the potential source for 11 cases, however another source (most often paint) was also mentioned in nine of these. Exposure to soil contaminated with lead – either through deliberate ingestion, indirect ingestion or

inhalation of dust – can result in raised BLC. A 1998 study reported that soil contaminated with pulverised lead-containing paint and petrol fumes was “at least or more important than lead-based paint” as a pathway of human exposure (56), and contaminated household dust, which can contain paint dust and tracked-in soil, has been suggested as the primary source of lead exposure in children in the US (5), although the authors found that floor dust was a greater contributor to children’s blood lead concentrations than soil alone. Several attempts have been made to quantify the correlation between blood lead concentrations and soil concentrations (55). The risk assessment of potentially contaminated land is a complex process and without environmental data it is difficult to interpret our finding from SLiC.

Soil may have been the main source of lead toxicity for some cases, it is more likely to have been a contributory factor alongside another more high-dose source such as paint, or consumption of soil may have been unrelated to the raised blood lead concentrations.

Ingestion of other non-food items

Reports of pica of other non-food items included batteries, sponges, pencils, plaster, moss etc. In many cases, the clinician indicated that the child ate more than one type of non-food stuff and that more than one source of exposure had been either suspected or confirmed.

These comments raise a number of interesting points. Many of the items suggested to be the source are unlikely to have contained lead. Batteries were suggested to be a lead source in three cases, including one where it was the only source suggested. Automotive and industrial batteries often contain lead, however portable batteries of the type used in a home and accessible to children rarely if ever contain lead (58-59) and lead is not listed as a potential risk from consumption of batteries by the NPIS (60). So it is unlikely that these cases of lead toxicity were caused by batteries. This strengthens the argument that the public and environmental health professionals, who are based in the community should be included in case management in order to fully investigate and remove/remediate the source, and that any findings should be shared across all the professional groups.

The causes of pica are not fully understood, but are thought to be of two separate streams: voluntary ingestion, where an individual enjoys the taste, odour or texture of the material ingested, or where it is culturally and socially acceptable; and involuntary, either as an impulse due to dietary cravings (such as iron deficiency) or due to other underlying physical or mental health conditions (37). In the questionnaire responses, where pica was not reported, paint and soil were sometimes still implicated as the source although the exposure pathway was not reported.

Ingestion of water

Despite PHOs in the UK routinely arranging testing of water supplies as part of the public health response to a case, water was marked as a source for only one child in Scotland. Paint was also identified as a possible source in this case. Many older (pre-1970) properties in the UK and RoI will have lead pipes within the building, although public water supplied to properties must meet strict water quality standards for lead concentrations (currently 10 µg/L in England and Wales) (61). It is not unusual for lead to be found in domestic drinking water due to the legacy of lead piping, however a review of the literature found only one incident in the US where a public water supply resulted in blood lead concentrations in children above 10 µg/dL. In this US incident, in 2001-2004 in Washington, DC, some water samples reached more than 100 ppb lead, which was associated with a 2.4 times increased incidence of elevated blood in children in high-risk areas compared to previous background rates (62).

Additionally, England, Wales and Northern Ireland have procedures in place that upon notification by water authorities of a raised water lead concentration, consideration should be given to whether blood tests are required; although blood tests are done rarely, none of these have resulted in blood lead concentrations>10 µg/dL. Private water supplies are subject to the same drinking water standards but could be more susceptible to lead contamination and there are limited case reports of lead toxicity in adults arising from private drinking water supplies (63).

Exposure via parental action

Two cases were linked to parental exposure: one via father's occupation (unknown) and one *in utero*. Maternal pica can lead to lead toxicity in the foetus, especially as many cultures accept eating of non-food stuff to combat the cravings and morning sickness associated with pregnancy, and there have been recommendations that there should be targeted screening of mothers for lead toxicity (64).

No information on exposure

Five children had no information on source or pathway provided on the forms, although one clinician marked that it was "not environmental", and none of these were reported to PHOs.

In cases of unknown lead source or potentially mistaken source (e.g. batteries), there is a concern that as the source has not been positively identified or remediated, the child remains at risk from further exposure.

All of the PHOs involved in the study have procedures for following up a notification of a child with elevated blood lead concentrations; PHE's includes an extensive list of potential sources to consider (25). Even where detailed investigations and site visits are

conducted, a source is not always found. Exposure may have occurred outside the home.

Passive exposure to lead-contaminated house dust was shown to result in blood lead concentrations of between 10 to 25 µg/dL (5), although this analysis was based on studies from the 1980s and 1990s when use of lead products had only recently been banned, so is unlikely to be as relevant in the UK and RoI today. However, accompanied by other low-level sources of lead, the cumulative exposure from dust could theoretically be high enough to reach blood lead concentrations over 10 µg/dL. Therefore, education and behavioural therapy to remove an exposure pathway remains a crucial way to cease further exposure and this was reported as a way of preventing exposure in about a third of cases.

Clinical presentation

Symptoms and treatment

Respondents were asked whether the child had any symptoms that could be suggestive of lead toxicity. In retrospect, this question was unclear, and clinicians may have interpreted this question as asking what signs / symptoms were present or whether these could be attributed to lead toxicity (65).

Additionally, it became clear during the analysis that several respondents stated that case had autism or ASD in free-text responses but did not tick the box for learning difficulties, development delay or behavioural problems. We discussed the issue with two paediatricians they agreed that it is difficult to resolve this as children with autism or ASD may not always have behavioural problems or learning difficulties.

Discussion with paediatricians confirmed that there is no consensus statement or clinical guidelines to prompt them to investigate possible lead exposure based on symptoms alone, without a history of potential lead exposure (65).

The question of whether all children diagnosed with a neurodevelopmental disorder should be screened for raised blood lead concentrations needs to be considered, in particular when their behaviour is not always observed and can be difficult to control. In 2001, a study of children with developmental and behavioural problems in the UK showed that children with behavioural and/or developmental problems had higher blood lead concentrations than controls, particularly children with blood lead concentrations above 10 µ/dL, which are commonly recognised as elevated (20).

In a study in two cities in northern England in 2014, 104 children with global developmental delay or learning difficulties were screened for raised blood lead concentrations and this identified only one child with blood lead concentration ≥10

µg/dL, although nine had concentrations above 5 µg/dL (33). The study recommended that blood lead concentrations should be a standard investigation for such children and that the cut off for environmental investigations should be 5 µg/dL.

Indications for blood lead testing

Indications for blood lead testing in a child could be either that the child is manifesting symptomatology that could be consistent with a raised blood lead concentration, such as convulsions, or that they have been identified as demonstrating behaviour, such as pica, that could put them at risk of exposure to lead. However, a diagnosis based purely on clinical signs and symptomatology is challenging as there are no pathognomonic symptoms for lead toxicity in children. The classical features of occupational lead poisoning, that have been recognised in adults since the industrial revolution, such as wrist drop and the 'Burtonian' blue line at the gingival margin seldom occur, if ever, in children with raised blood lead concentrations (69).

Most clinicians who responded to the questions on the reason for blood lead sampling gave pica as the reason for testing. The overall prevalence of children with pica in the UK population is unknown, however pica is considered to be ‘normal’ behaviour with 50% of children aged 18 to 36 months expected to display the behaviour. So, at what point does pica behaviour become a concern for both the parent and the clinician?

Table 3 shows that a significant number of children were referred to a paediatrician by ‘other’ professional groups, rather than a general practitioner or hospital clinician. These included other paediatricians, a hospital emergency department, a speech and language therapist, public health officials (due to household contacts) and schools. This illustrates the wide range of ways that lead toxicity may manifest and that there may be an opportunity for awareness raising in these other various professional groups.

Blood lead concentrations of cases

The mean blood lead concentration for the cases reported was 35 µg/dL (median 21.2µg/dL), This is lower than the mean blood lead concentration found in the six children aged 0-5 years reported to the NPIS in 2011-2012 (mean 70.9 ± SD of 106.4 µg/dL, range 9–308 µg/dL) (67). This discrepancy may reflect that the case definition for the SLiC study included cases with BLC ≥10 µg/dL (or 0.48 µmol/L), whereas NPIS is likely to only receive calls about more severe toxicity; this is reflected in our data, where clinicians indicated that NPIS / clinical toxicologists were only consulted for children with BLCs greater than 30 µg/dL.

Public health response to case notification

Clinician reporting to environmental/ public health

Of the 32 case reports from the BPSU, PHOs reported being aware of only 13 (Figure 5). Public and environmental health structures are complex, and vary in different parts of the UK. Paediatricians may not always be aware of their local PHO or the role they play in environmental hazard management.

The covering letter that the SLiC study team sent to paediatricians included contact details for their local PHO. Paediatricians that decided against informing the PHOs were asked to give their reasons; responses included not being aware that a PHO should be informed, lead levels being 'mildly' elevated or having resolved already, and being advised that it was "not necessary unless unusual water supply or old house". Generally, if the PHO had been informed then the local authority environmental health was also informed. From these findings it seems that the role PHOs could play in managing cases with raised blood lead concentrations is not well known by paediatricians.

Public health role: Identification of others at risk and source

A key role of the public and environmental health professionals is to investigate and manage the source of lead, if identified. Where a PHO had been informed about a case of childhood lead toxicity, 81% had a likely source identified; this fell to 53% where a PHO had not been informed. Some of this difference may be reporting bias as SLiC received information on source from the PHO more often than the clinician. However, it still indicates that clinicians are less likely to identify the source of the child's exposure if a PHO is not involved. As prevention of further exposure is a key part of the management for children with raised blood lead concentration (68), this is a worrying finding and other children or vulnerable groups may be exposed in the setting in the absence of public health intervention.

Testing of all these possible sources for presence of lead can be complex and in some cases costly to organise. In the UK, different agencies and departments are responsible for regulation of different products and these often change depending on whether the property/resource in question is rented publicly or privately, or owner-occupier. Understanding roles and responsibilities and legislation is crucial to ensure that the correct people are involved, and even then, specialist knowledge, training and equipment may not be readily available to fully investigate a case.

It is difficult to be sure that products are the sole or main cause of the toxicity, even when they are identified as containing lead. British Geological Survey data on Normal Background Levels of lead in soil in England demonstrates how lead is ubiquitous in our soils, with many areas being significantly above the low risk soil screening value

(category 4 screening level) for residential properties (with home-grown produce) of 200 mg/kg (69). Any such environmental data requires careful interpretation to avoid making false positive conclusions about the source of a child's lead exposure. A pragmatic approach needs to be taken when deciding on the number of samples to take, based on pre-existing intelligence on the likely source; this is why site visits, sensitive discussions with parents and exposure questionnaires are useful.

Public health role: Remediation and management of source

Once a source has been identified, there are many options for protecting the child from further exposure, as seen in Table 8. Removal of the lead hazard was the most commonly reported action taken, often by stripping away lead paint, followed by behavioural change advice such as closer supervision to prevent pica, which serves to remove the exposure pathway. In some more severe cases, the family moved home to a safer environment such as a newer house.

Investigating and paying for remediation of an identified source may involve a range of different agencies and legislation and is rarely straightforward.

PHOs, working closely with local authorities and community organisations, are well-placed placed to assist paediatricians and other clinicians with environmental investigation and management.

SLiC public health legacy

SLiC led to a review of the PHE public health response to childhood lead toxicity, including surveillance, response procedures and multi-agency collaboration in each country.

Public health resources and support materials

The increase in reported cases of raised blood lead concentrations in children has been sustained post-SLiC due to reporting from SAS laboratories (1) Analysis of SLiC results and feedback from PHOs on the management of cases of raised blood lead concentrations has brought up learning points that can be fed into guidance and procedures.

The suite of support materials developed at the start of the SLiC study was used by HPA (now PHE) staff, clinical and environmental health professionals and the public. For example:

- PHE staff used the resources to guide their public health investigation
- clinicians were informed of the FAQs for paediatricians
- environmental health staff signposted to legal standards, accredited laboratories and sampling methods

- the public information about lead.

The lead action card and other PHE guidance is being updated. It is not yet available on the PHE website for public access, but is available to professionals..

Planned work includes factsheets for the public and clinicians on environmental public health investigation, and groups at higher risk.

Laboratory reporting

The link between PHOs and biochemistry laboratories in England, Scotland and Wales has proved to be a success and reporting has continued beyond the data gathering phase of SLiC. In England, this is the first systematic, direct reporting of laboratory results for non-infectious diseases to public health teams.

A recent evaluation of the pilot arrangements in England has shown this to be working efficiently with demonstrable public health benefit, such as quicker notification periods to public health of a case (1) The laboratory reporting arrangements will therefore be sustained and a working group is considering whether to expand it to other metals, chemicals, non-infectious environmental hazards, or vulnerable groups.

Public Health Wales also finds that the biochemical laboratory reporting arrangements are working successfully, with data being received on a six-monthly basis. New relationships have been established between hospital laboratories and the HSE in RoI.

Improved reporting and collaboration between organisations

Project staff involved in SLiC have found that cross-border working, sharing resources and experience between public health teams useful. Prioritisation of lead hazards and raised blood lead concentrations differs between countries and SLiC has facilitated sharing of these approaches.

PHOs felt that reporting and multi-agency collaboration in particular has improved, but it is difficult to attribute any improvements to SLiC alone, as work was already underway in England, Wales and Northern Ireland.

Public Health Wales reported that although paediatricians were already reporting cases of elevated blood lead to them, the formal relationship established during SLiC has improved. Relationships have also been strengthened with the laboratories.

The HSE in RoI systematically assessed their current reporting arrangements and considered that any diagnosed cases of raised blood concentrations in children would most likely have been picked up during SLiC; however, as only one case was found the potential scale of the disease is not thought great enough to warrant any changes.

Raised awareness among professionals

SLiC highlighted differences in reporting of non-infectious and infectious diseases to public health. The study group contacts in Wales, Northern Ireland and RoI all reported that SLiC resulted in improved public health response to lead poisoning and that it also provided a useful lever for discussing lead hazards in schools, education authorities and water companies. In Wales, where significant work on lead was ongoing parallel to SLiC, there is a lead subgroup under the health partnership (30) that publicises the risks during the WHO's lead awareness week.

Dissemination of findings

From pre-study initiation to date, PHO staff have been raising awareness of SLiC and lead poisoning, and disseminating findings to a variety of professional groups. Formal presentations, posters and papers dedicated to SLiC are listed in Table 2, however SLiC has also been mentioned as part of presentations and training on other occasions.

Professional groups that have received information or training in one form or another, include:

- paediatricians, community paediatricians and toxicologists
- school nurses and education authorities
- water companies and regulators
- environmental health officers
- public health professionals
- academics
- parents and members of the public.

The final findings of SLiC will be further disseminated via the BPSU and peer-reviewed journals.

Conclusions and recommendations

Surveillance and reporting of clinically diagnosed cases

SLiC has collected data on 46 confirmed cases of children with raised blood lead concentrations across the UK and the Republic of Ireland over 24 months (2010 -12). Although more cases were reported than in previous years through statutory public health notifications and laboratory reporting, this is still a likely underestimate of the numbers of children affected.

Although uncommon, lead toxicity can have a significant health impact and is preventable. Of those cases reported, most were via the laboratory route. This offers the most scope for robust future reporting of lead cases.

Recommendation 1: Continue laboratory surveillance for raised blood lead concentrations in children.

For England, surveillance could continue into the future by including lead into the PHE Environmental Public Health Tracking (EPHT) and Environmental Public Health Surveillance System (EPHSS), and equivalent systems in other parts of the UK and RoI. The surveillance should include sources of lead exposure, in order to continue to build the evidence base in the UK, and provide a stronger basis for hazard and risk assessment.

After the SLiC study data collection was completed, a laboratory surveillance system was piloted in PHE, and has now been formally evaluated (1). Continuation and expansion of lead exposure surveillance are currently under consideration.
The reporting remains at the 10 ug/dL(0.48 µmol/L) level, which is the threshold currently being used by PHE to stimulate case management. It is clear that toxic effects of lead occur at levels below 5 ug/dL (14) and, therefore, the reporting level is being kept under review by PHE.

Reporting to public health organisations (PHOs)

Inclusion of PHOs in a case's management resulted in improved identification of the source and therefore prevention of further exposure. We have also shown the importance of public health professionals in identifying other individuals at risk who may be sharing an environmental exposure or copying risky behaviour.

Paediatricians, general practitioners and other clinicians have a role in the advocacy for their patients and families, and in working with public health and environmental health

organisations on prevention and mitigation of lead exposures. Responses showed that many clinicians are not aware of the role of PHOs for non-infectious environmental hazards, for example in confirming the source of exposure using environmental testing, or how to contact them.

Recommendation 2: Build and strengthen relationships between public health, paediatrics and other related clinical specialties to improve reporting of children with raised blood lead concentrations, and provide a more timely public health response.

It is recommended that all cases of childhood elevated blood lead concentration be referred to PHOs, even if the source of exposure appears to be obvious, in order that remediation for the case and other vulnerable children can take place(11).

Infectious disease surveillance offers some possible models. One mechanism for this could be via the laboratories using a similar notification system to that used for infectious diseases. For example, the blood test result for lead could also include advice that the clinician should contact their local PHOs for further public health advice, and investigation and management of the potential source and others potentially exposed.

Identification and testing of children at high-risk of lead exposure

This study considered only those cases presenting to a clinician. Many children with raised blood lead concentrations have no symptoms, or non-specific symptoms, and may not present to clinicians. Targeted screening is carried out in some US states for those at high risk of lead exposure (70).

Recommendation 3: Review the need for targeted screening to identify children at high-risk of lead toxicity.

A formal review of whether targeted screening is justified should be considered, as many children with raised blood lead concentrations do not have symptoms.

Sources and routes of lead exposure

This study has improved our knowledge of the risk factors and diagnosis pathways. The results indicate that a significant majority of these children are reported to have pica, which was thought to be the underlying reason for exposure to lead-containing compounds. Paint was the most common suggested source of lead identified, with soil second. Many other sources were suggested, some of which are unlikely to have included lead. The results also suggest that those children from families of lower socio-economic status and black and ethnic minorities are over-represented, as well as children with neurodevelopmental issues.

Remediation options used in each case varied. Limitations of the study were that environmental investigations were often not carried out, and the source of exposure reliant on history of observed behaviours. However, these findings are consistent with risks identified in research studies and screening/hazard assessment in other countries.

Despite the lack of information on environmental investigations and sampling to confirm the primary source of exposure for the cases, it would seem credible that the source of exposure for the majority of cases in the study are exposure to old lead-containing paint. Pica of soil and other non-food items were also possible exposure pathways.

The following recommendations (4 to 8) address prevention of lead exposure in children. They also address the need to investigate and reduce exposures where these have already occurred.

Recommendation 4: Update the advice and guidance for the public, healthcare and environmental health professionals on lead hazards and risks, and prevention or mitigation of environmental exposures.

A multi-agency arrangement is required working across PHOs, clinicians (paediatrics, occupational health, toxicologists), Environmental Health, Drinking Water Inspectorate, Department for Environment, Food & Rural Affairs (Defra) and others.

Whilst some guidance has been developed, consideration should be given to making relevant material available in one place easily accessible to members of the public and professionals. In some cases it will be necessary to develop new guidance to address gaps in information. Box 1 outlines some examples for consideration.

Box 1: Examples of potential guidance on prevention or mitigation of environmental exposure to lead

Information for the general public
Some information is already available to the public, but consideration should be given to making it more readily available electronically, for example through the NHS Choices and the GOV.UK websites. Consideration should also be given to making information on lead more easily accessible to the public through multiple routes. Whilst a public leaflet is available on the gov.uk website on lead in paint (71), this could be made more easily accessible, for example in DIY stores, making homeowners aware of safe DIY practice and ensuring that paintwork in older properties is maintained in good condition to ensure that children are not exposed to paint chips or dust. The Drinking Water Inspectorate (DWI) and water companies provide information on lead pipes.

International Lead Poisoning Prevention Week, provides an opportunity to raise awareness and publicise materials for the public and professionals. For example. Public

Health Wales uses this to remind the public and professional groups of the hidden dangers of lead http://www.who.int/ipcs/lead_campaign/en/. This approach could be adapted by other PHOs.

Hobbyists
Awareness raising and making information easily accessible to hobbyists, through relevant groups, and at the point of sale of hobby materials is important.

Education for parents with high-risk children
Advice and information could be targeted at families at higher-risk from environmental exposures, for example poorly maintained older properties, or from behaviours such as pica. These families and children are often already known to health and social care professionals.

Improved advice on pica by health and social care professionals
Awareness raising amongst healthcare workers, including health visitors and primary care staff to ensure that information is provided to pregnant women, parents and carers on importance of preventing exposures from pica.

Maintain compliance of safe working with lead in occupational groups
Occupational exposures are the responsibility of the Health and Safety Executive (http://www.hse.gov.uk/) and there is specific legislation for people that work with lead (CLAW). This study demonstrates that there are still areas where exposures to workers and their families still occurs.

Information for landlords
Landlords are responsible for several aspects of home safety under the HHSRS. Information on lead alongside other hazards should be provided to landlords.

Recommendation 5: Review the evidence for making homes in the UK and RoI 'lead safe'.

Consideration should be given to reviewing the evidence for a 'lead safe' policy in the UK, for example by removing sources of lead in homes and preventing exposure, particularly in at-risk groups. Different legislation and regulations apply in different parts of the UK and RoI. In England and Wales for example, the Housing Health and Safety Rating System(HHSRS) is a risk-based assessment tool to help local authorities identify and protect against potential risks and hazards to health and safety in residential properties (50). Guidance was developed to protect mainly people in rented accommodation from unsafe properties and lists lead as one of the 26 hazards. However, there are limited resources and it is unclear whether removal of lead within private homes is justified, unless there is a known risk.

Environmental investigation and control measures

Recommendation 6: Update advice for environmental health officers on environmental investigations & control measures, so that local authority response is appropriate and consistent.

The UK Chartered Institute of Environmental Health should consider whether guidance or a toolkit for practitioners should be developed for environmental investigation for lead. The guidance should also include information on the legislation and the regulation for enforcement and remediation when a child is found to have a raised blood lead concentration.

Clinical diagnosis and investigation

Currently, there is no guidance available for paediatricians and other clinicians in the UK or RoI on when to test children for elevated blood lead concentrations. As a consequence, a number of enquiries from paediatricians were received during the study regarding investigation and follow up of the cases of children with raised blood lead concentrations.

This study identified differences in the clinical investigation of raised blood lead concentrations in children with neurological difficulties; it also identified that these groups are over-represented among the cases notified. Pica was the most common symptom triggering investigation of blood lead concentrations. Children with neurological difficulties were investigated in some areas, but in others they were not. In the future, clinical investigation of blood lead is likely to become easier, as many children with neurological and other conditions are already having blood samples taken for investigations such as genomics.

Recommendation 7: Update advice and guidance for paediatricians, general practice, and other clinicians on the diagnosis, investigation and clinical management of raised blood concentrations.

There are a number of areas where clinical guidance is required particularly for children at higher risk of exposure, or with neurological difficulties. This should include the public health measures to prevent or reduce environmental exposures. For example:

Guidelines should be developed for paediatricians on indications for testing children for raised blood lead concentrations. The development of these guidelines should consider the evidence for the targeted screening of children with neurodevelopmental issues in line with the American Academy of Paediatrics guidance (70).

Guidance should be developed for GPs and other health professionals – including speech therapists, health visitors, school nurses. This should include information on

primary prevention, advising parents and carers on avoiding exposure and indications for referring a child to secondary care based on exposure history, clinical symptoms or index of suspicion. This should also include the advice that all children identified with a raised blood lead concentration be referred either to a clinical toxicologist or to a paediatrician for further management.

Clinicians and occupational health physicians that are treating an adult for lead toxicity should consider the potential that family members may also have been exposed. This study has found examples where children have been exposed via a parents occupation. Three children in our study were exposed via a parent's occupation (likely bringing lead home on clothes/footwear) or parent's hobby (using lead inside the home).

Cost-benefit analysis

Information on the costs and benefits of lead toxicity is not available for the UK. Cost-benefit analyses in other countries have been conducted that consider both healthcare costs of lead toxicity but also societal costs, such as reduced IQ, delinquency and criminal behaviour.

Recommendation 8: Consider analysis of the costs of investigation and management of raised blood levels in children in the UK and RoI, and the potential costs and benefits of prevention, in order to provide evidence for the most cost-effective strategy.

This could include:

- NHS costs: testing, treatment, chelation, hospitalisation, behavioural therapy, staff hours
- environmental costs: sampling, remediation works, staff hours
- incidental costs: behavioural changes, accommodation in a hotel, legal advice etc

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List of acronyms

ACCLPP	Advisory Committee on Childhood Lead Poisoning Prevention
ALSPAC	Avon Longitudinal Study of Pregnancy and Childhood
ASD	Autism Spectrum Disorder
BLC	Blood lead concentration
BPSU	British Paediatric Surveillance Unit
CDC	US Centers for Disease Control and Prevention
CHIRP	Chemical Incidents Reporting Programme
CNF	Case Notification Form
CRCE	Centre for Radiation, Chemicals and Environmental Hazards
DA	Devolved Administrations
DEFRA	Department for Environment, Food & Rural Affairs
DWI	Drinking Water Inspectorate
EPHSS	Environmental Public Health Surveillance System
EPHT	Environmental Public Health Tracking
ERG	Epidemiology Review Group
FUF	Follow-up Form
HPA	Health Protection Agency
HPS	Health Protection Scotland
HSE	Health Service Executive, Republic of Ireland
IMD	Index of Multiple Deprivation
LSOA	Lower Super Output Area
NHANES	National Health and Nutrition Examination Survey
NPIS	National Poisons Information Service
PHA	Public Health Agency for Northern Ireland
PHE	Public Health England
PHO	Public Health Organisations
PHW	Public Health Wales
PII	Patient identifiable information
RoI	Republic of Ireland
SAS	Supra-Regional Assay Service
SATs	Standard Assessment Tests
SLiC	Surveillance of Elevated Blood Lead in Children
UK	United Kingdom
US	United States of America
VOA	Valuation office Agency
WHO	The World Health Organization

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