

Adfam is the national umbrella organisation working to improve life for families affected by drugs and alcohol.

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MEDICATIONS IN DRUG TREATMENT: TACKLING THE RISKS TO CHILDREN ONE YEAR ON

Executive
Summary


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Foreword

This report builds on our previous work, *Medications in Drug Treatment: Tackling the risks to children*, in considering the risks posed to children from substitute drugs prescribed to those struggling with opioid addiction – and proposing steps for minimising these risks. In the foreword to last year’s report I posed the question: ‘On a systemic level, are we doing all that we can to make sure these incidents don’t keep happening?’ I answered that question with a no; unfortunately, I must offer the same response this time around too. Of course, a year is not a long time to effect or even observe system change, and we have found some examples of encouraging practice and attitude at a local level.

It should go without saying that the death of any child is a human tragedy. Reports and investigations triggered by these tragedies, from the expansive Laming report following the murder of Victoria Climbié to the serious case reviews (SCRs) considered in this document, generally highlight a systemic and cultural failure from services which have not worked closely enough with each other in safeguarding vulnerable children.

There is an aphorism from the world of business management – ‘culture eats strategy for breakfast,’ which I believe has some relevance here. We have found some encouraging examples of new practice in local areas – for instance specialist midwives in drug services, and joint-working protocols between drug services and health visiting teams – which have clearly been driven by an understanding of the strategic complexity of safeguarding children. Hopefully these sound strategic decisions will translate into an everyday working culture of professional curiosity and healthy scepticism, which we believe is essential in achieving the aim of protecting children from risk.

The new statistics are shocking. The scale of the issue is much larger than originally anticipated. Our report last year identified 23 incidents of ingestion and 17 child deaths between 2003 and 2013; mortality data and hospitalisation data uncovered since show the real number of ingestions to be in the hundreds, and the number of deaths over 100. This more realistic estimation adds weight and urgency to the policy and practice recommendations in the original report; all of which still stand.

In any debate on this matter it’s important to keep sight of the fact that OST is an effective intervention with a substantial evidence base, both clinical and anecdotal; and the vast majority of those who use it do so safely and appropriately. Similarly, the majority of practitioners working to facilitate recovery and safeguard children are highly competent and passionate individuals, doing their best in a time of financial and structural constraint.

By the end of 2015, Adfam will have worked with multi-agency teams in 19 local authorities to develop joined-up and strategic approaches to better protect children whose parents or carers use OST medications. This has been extremely valuable in terms of both uncovering (and sharing) good practice, and together identifying areas for development. It is my hope that this practical but strategic work at a local level combined with the learning in this report will be a positive force in preventing some of these all too familiar future tragedies from occurring.

Vivienne Evans OBE
Chief Executive

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Background

Adfam's report, *Medications in Drug Treatment: Tackling the risks to children*, was published in April 2014. It was the first report in the UK to examine the prevalence of child ingestions of medications used in opioid substitution therapy (OST), and make recommendations to effectively minimise this risk.

It found that between 2003 and 2013, there were 20 serious case reviews (SCRs) (involving 23 children) in England and Wales, following the ingestion of OST medications by a child – 17 of these were fatal. Eighteen involved methadone, and one involved buprenorphine. The research highlighted a clear knowledge gap, both amongst professionals and parents, of the dangers of OST drugs to children, and showed that learning from these cases was not being shared. Furthermore, it found that these risks were failing to be adequately managed in practice, and safeguarding concerns were not being sufficiently prioritised in reality.

OST medications can present risks to children that other prescription drugs do not: for example, toxicity in very small doses, possible attractiveness to children, chance of unsafe storage in sometimes chaotic households and the proven use of methadone as a pacifier. The rightful place of these medications in a recovery orientated treatment system, however, must not be endangered, and the majority of people who are prescribed and use OST do so safely.

Aims

The purpose of this 'One Year On' report is to:

1. Describe and assess the progress made in implementing the recommendations of the original report.
2. Provide practice examples from services which have taken steps to address the issue.
3. Provide updated information, data and evidence.
4. Outline Adfam's progress in disseminating and championing the recommendations of the original report.
5. Provide a follow-up to the original report's recommendations: expanding on the issues identified and making new recommendations to address them.

Methodology

A literature review was conducted to provide updated information, data and evidence to further inform the debate. To estimate the true prevalence of child ingestions of OST medications, mortality statistics between 2003 and 2013 were sought from the Office for National Statistics (ONS), the Northern Ireland Statistics and Research Agency (NISRA)¹ and the National Records of Scotland (NRS). Full overview reports of new SCRs involving OST ingestion since April 2014 were sought via the NSPCC website and relevant Local Safeguarding Children Boards' websites; revealing three new cases where a child had ingested methadone.

A media review was also carried out to identify other cases which had not resulted in a SCR. Evidence of current ways of working and changes implemented in response to the findings of the original report were provided by seven treatment services. Local authorities that had experienced a SCR were contacted to provide information on progress since the case, to which four responded.

Opioid substitution therapy

OST is a medical intervention whereby long-acting opioid medications (primarily methadone or buprenorphine) are prescribed in replacement of illegal opioid drugs (such as heroin). It aims to reduce or prevent withdrawals, provide an opportunity to stabilise drug use and lifestyle, and offers an opportunity for therapeutic work with a client.² OST can enable people to become free from dependence on illicit substances, and provide the opportunity to pursue goals, such as employment or education, as part of a wider recovery process. It has been found to decrease drug use and mortality, inspire high retention rates, improve quality of life,³ reduce crime and limit the spread of blood-borne viruses.⁴ This report does not seek to comment on the efficacy of OST generally as a tool for treating opioid dependence. The evidence overwhelmingly shows that it has a rightful place in our recovery-orientated treatment system.⁵

Official guidance from the National Institute for Health and Care Excellence (NICE), Technology Appraisal 114, states that decisions on which medication to prescribe should 'take account of the person's lifestyle and family situation (for example whether they are considered chaotic and might put children and other opioid-naïve individuals living with them at risk)',⁶ and recognises the high mortality risk associated with methadone, particularly in opioid-naïve people.⁶ OST can be prescribed for take-home use or on a 'supervised consumption' regime, whereby service users are required to take the medication in the presence of a health professional, such as a pharmacist. Guidance recommends that all clients be on a supervised consumption regime for at least the first three months; which can then be relaxed to reflect compliance with treatment, and take-home doses allowed more frequently. The Department of Health has suggested that supervised consumption is the 'best guarantee' the medicine is used as directed, and advises against take-home doses where there are concerns over the safe storage of medications at home, 'or potential risks to children.'⁷ However, despite this guidance, findings from the original report suggested that safeguarding children from the risks posed by OST medications was failing to be sufficiently prioritised and addressed in practice.

¹ Statistics for 2013 were not available from NISRA at the time of request. This set of data covers 2003-2012

² Advisory Council on the Misuse of Drugs (2014) Time limiting opioid substitution therapy. (Response to question posed to the Recovery Committee on behalf of the Inter-Ministerial Group on Drugs) (Web resource)

³ Pihkala & Sandlund (2015) 'Parenthood and opioid dependence,' 6 Sub abuse and rehab 33

⁴ Reimer et. al. (2016) "The Impact of Misuse and Diversion of Opioid Substitution Treatment Medicines: Evidence Review and Expert Consensus," 22(99) Eur Addict Res 106 (Available first online)

⁵ National Treatment Agency (2012) Medications in recovery: Re-orientating drug dependence treatment

⁶ NICE (2007) Technology Appraisal 114: Methadone and buprenorphine for the management of opioid dependence

⁷ Ibid

Key Findings

Serious case reviews

SCRs provide an opportunity for agencies and individuals to learn lessons and improve their methods of working, in order to effectively safeguard and promote the welfare of children.⁸ Since the publication of the original report, two more SCRs involving child OST ingestions have been published in Blackpool and Oxfordshire. Blackpool's 'Child BT' (2015) and Oxfordshire's 'Child H' (2014) SCRs bear striking resemblance to those examined in the original report and to one another: both involve a young child's accidental ingestion of methadone ('Child BT' was two years old, and 'Child H' 21 months), which was prescribed to the mother. One ingestion proved fatal (Blackpool, 'Child BT'), whilst the other child made a full recovery (Oxfordshire, 'Child H'). In the Blackpool case, it was later discovered the parents had been selling methadone, and the drug was found in a variety of receptacles in the home, including children's feeding cups and fruit juice bottles. In the 'Child H' SCR, the mother left the methadone bottle (with a child resistant cap) in her handbag in a room with the child unattended, and assumed the child must have drunk it.

Media reports also revealed that a SCR is underway in Birmingham, following the death of a 23-month old child, after being deliberately administered

methadone by his mother 'to help him sleep.'⁹ The three cases share many commonalities: the bias towards younger children (the median age of the children subject to SCRs in the last report was two years old), the feature of unsafe storage and an insufficient appreciation of the dangers of OST drugs to children. Methadone prescribed to the mother was implicated in all three cases and the families were in contact with a range of different agencies. Recommendations focused mainly on: improving information-sharing, inter-agency collaboration and professional awareness of the risks associated with OST; recognising disguised compliance,¹⁰ and the professional tendency towards over-optimism.

The revelation of new SCRs involving harm to children after ingesting OST drugs – as well as the similarities between these cases – shows that the opportunity for learning in the review process is not being utilised. SCRs do not always discuss the details of a single event in which a child has come to harm, but focus on professional engagement with the family. The then Department for Children, Schools and Families found that '*local overview reports often provided insufficient information to achieve a clear understanding of the case and the incident which led to the children being harmed or killed.*'¹¹ This could lead to limitations when trying

to improve policy and practice to prevent children coming to harm. The need for the dissemination of learning from individual cases to raise awareness of the risks thus remains, together with a nationally-driven, coordinated response to the problem.

The number of children affected by parental substance use

In 2003, the ACMD estimated that there were 250,000 - 350,000 children of problem drug users in the UK.¹² A later study¹³ found that around one million children lived with an adult who had used an illicit drug in the past year, and just under half a million with someone who had done so in the past month. The number of children living in a household where the only adult was a drug user was found to have more than doubled between 2000 and 2004/5, and 334,000 children were estimated to be living with a dependent drug user. Both these figures are, however, likely to be underestimates: the former is based on an extrapolation of treatment data alone, and the latter relied on self-reported service user evidence. The true number of children affected by parental substance use is unknown.

The number of people with parental responsibility receiving a prescribing intervention

A Freedom of Information request revealed that, in England, the number of people with parental responsibility receiving an OST prescribing intervention had risen from 60,596 in 2011/12,¹⁴ to 61,928 in 2012/13. Nevertheless, this

information does not provide an indication of the number of households in which OST represents a risk factor, given that we do not know how many of these people are allowed take-home doses. This is an identified gap in need of further research.

Hospitalisations and diagnoses of methadone poisoning in children

Data from the Health and Social Care Information Centre (HSCIC) show that between 2003 and 2013, at least 310 children (aged 0-17) were hospitalised due to methadone poisoning,¹⁵ and a further 18 children in 2013/14, including seven under-fives.¹⁶ These figures provide a much needed realistic estimation of the number of child ingestions of OST. They do not, however, give a clear picture of the scale across the country, and figures for buprenorphine are not available. In addition, prior to the 2012/13 report, children aged 15 and above were not accounted for (the age breakdown being 15-59 years).

Child mortality data where deaths involved methadone and buprenorphine

UK data for all methadone and buprenorphine deaths registered between 2003 and 2013 involving persons up to and inclusive of the age of 18 was requested from the Office for National Statistics

⁸ Department for Children, Schools and Families (2010) *Working together to Safeguard Children Chapter 8: Serious Case Reviews*

⁹ *The Mirror* (5 March, 2015) 'Fenton Hogan: Serious Case Review launched into tragic toddler's death.' (Web resource)

¹⁰ Disguised compliance involves a parent or carer giving the appearance of co-operating with services to avoid raising suspicions, to allay professional concerns and ultimately to diffuse professional intervention. (See: Reder et. al. (1993) *Beyond blame: Child abuse tragedies revisited*. London: Routledge)

¹¹ DCSF (2008) *Understanding Serious Case Reviews and their Impact: a biennial analysis of serious case reviews between 2005 and 2007*

¹² Advisory Council on the Misuse of Drugs (2003) *Hidden Harm*
¹³ Manning et. al. (2009) 'New estimates on the number of children living with substance misusing parents: results from UK national household surveys,' *9 BMC Public Health* 377

¹⁴ HC Deb 29 October 2013, vol 569, cols 439-440

¹⁵ HSCIC, *Hospital Episode Statistics, Admitted Patient Care – England, 2003-13* (Appendix 1). Until the 2012/13 report, the age breakdown was: 0-14 and 15-59. Consequently, the number of children aged 15 and above diagnosed with methadone poisoning pre-dating this report is unknown

¹⁶ HSCIC (2014) *Hospital Episode Statistics, Admitted Patient Care – England, 2013/14*

Themes from SCRs and local practice evidence

(ONS), the National Records of Scotland (NRS) and the Northern Ireland Statistics and Research Agency (NISRA), which hold information on all registered deaths. The findings are summarised in the table below.

Total number of deaths by methadone and buprenorphine poisoning registered in the UK between 2003 and 2013 for those up to the age of 18 inclusive

Country	Methadone	Buprenorphine	Total
England & Wales	72	1**	73
Scotland	35	2	37
NI*	0	0	0
Total	107	3	110

* Figures for 2013 were unavailable at the time of request. Data captured 2003-2012

** NB Data includes the 1 death confirmed as involving an under-18 year old; there were 19 deaths of 15-19 year olds. See text.

Taking this new data from all four countries of the UK, it is evident that the 17 deaths uncovered by the SCRs in the original report constitute a fraction of the total number of child deaths attributed to OST medications during that period. Between 2003 and 2013, at least 110 persons aged 0-18 inclusive died from methadone or buprenorphine poisoning in the UK. The ONS data on buprenorphine-related deaths was categorised by two age brackets: 0-14

¹⁷ SCRs are conducted when a child comes to serious harm or dies and abuse or neglect is suspected

and 15-19. No deaths were registered in the 0-14 age category. Nineteen deaths were registered in the 15-19 age category, but only one was confirmed as involving an under-18, after having cross-referenced the data with SCRs. However, it is likely that this is not the only one. Of the 72 methadone-related deaths in England and Wales, only six resulted in a SCR – meaning that 66 did not.

The reason why some cases triggered a SCR whilst the majority did not is unknown. It is open to speculation whether this is as a result of varying thresholds in local authorities, or differences in the facts of the cases, such as a lack of professional involvement or suspected abuse or neglect.¹⁷ In the absence of a SCR or further information relating to these deaths, the respective number of cases of intentional administration and accidental ingestion cannot be ascertained, nor can we know to whom the methadone was most commonly prescribed, or on what regime i.e. supervised consumption or take-home doses. Consequently, the data, whilst providing a welcome estimate of the problem, is nonetheless limited in terms of what it tells us about patterns of child ingestions, and which policies and practices to prioritise in response.

The finding that the majority of children who ingest OST drugs are, in fact, adolescents, rather than very young children as the SCRs would suggest, means more research is needed to determine how and why adolescents are ingesting OST medications.

This research has identified an insufficient awareness of both the impact of parental substance use generally, and the specific risks posed to children by OST medications. The recommendations made in the original report have yet to be embedded, and the failure to do enough to raise awareness of the issues and manage risks is evidenced by the continued hospitalisations, deaths and SCRs. Evidence received of local practice shows that isolated efforts are being made by local authorities and services to minimise the risks to children posed by take-home OST medications. The key findings are discussed below.

Safety and addressing intentional administration

Whilst an appreciation amongst drug treatment services of the importance of supplying a safety box and discussing safe storage with clients is clear from the evidence submitted, the same could not be said of an awareness of intentional administration. There was little to suggest that intentional administration is being consistently and sufficiently addressed by services, with few tackling the issue explicitly in leaflets and safety advice. Messages around safe storage are futile if there is a possibility that the parent is deliberately administering drugs to the child. In light of yet another SCR involving the use of methadone as a means of pacifying the child (Birmingham, unpublished),¹⁸ this area is in need of further research and a greater level of awareness.

Dispensing and prescribing practices

Whilst a variation in dispensing and prescribing practices was identifiable from the local evidence gathered, it also indicated that it is common practice for services to allow take-home doses to clients after the initial three month period of supervision recommended by guidance comes to an end. Only one service provided evidence of a more gradual regime; whereby patients wait a further 12 weeks following the initial three month period before being considered for weekly dispensing, to allow for a more planned treatment pathway. Two local areas reported prescribing buprenorphine as the first choice to all parents in treatment; one if the child was under five, and the other if the client had a child of any age. Both services reported positive results, and little resistance from clients. The literature review revealed evidence which suggests that methadone has a higher risk of mortality than buprenorphine, and this is supported by the difference in the number of child deaths related to the two medications. However, no evidence currently exists that clearly demonstrates the respective benefits and risks of prescribing methadone and buprenorphine specifically to parents in treatment.

Joint-working, information-sharing and professional competency

The two published SCRs identified a number of ‘missed opportunities’: failures in communication and inter-agency working and a lack of professional

¹⁸ Facts sourced from media reports: *The Mirror* (5 March, 2015) ‘Fenton Hogan: Serious Case Review launched into tragic toddler’s death.’ (Web resource)

curiosity, challenge, and appreciation of risk. This research suggests that practitioners must be trained, and equipped with the skills necessary to employ professional curiosity and challenge confidently and respectfully. This was recognised and encouraged in much of the evidence gathered from local areas. Similarly, the action plans, copies of guidance and policies submitted, demonstrated efforts to improve joint-working and information-sharing, and several advocated home visits as a useful tool to effectively safeguard children from the risks of OST. In order for practitioners to have a ‘whole picture’ of the family, inter-agency cooperation and communication is crucial. In line with *Working Together*¹⁹ and NTA guidance,²⁰ local authorities should consider the creation of inter-agency joint protocols to facilitate information-sharing, and better manage risk.

¹⁹ HM Government (2010) *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children*

²⁰ National Treatment Agency for Substance Misuse (2010) *Supporting Information for the Development of Joint Protocols between Drug and Alcohol Partnerships, Children and Family Services*

Adfam’s work

Since the publication of *Medications in Drug Treatment: Tackling the risks to children* in April 2014, Adfam has continued to work to raise awareness of the issue, and share best practice. This has included presenting the findings and recommendations to hundreds of practitioners from the health, social care and drug treatment sectors, and meeting with several organisations, including Public Health England, to seek to embed the report’s recommendations. Best practice training was also delivered to four pilot local authorities in September 2015, and will be delivered to an additional fifteen local authorities before 2016. The training is aimed at a multi-disciplinary audience, and its objective is to help local authorities develop a blueprint to enhance local practice regarding safeguarding the children of OST-prescribed service users, based on the learning from national SCRs; including how to conduct appropriate risk assessments, consider the evidence base on the impact of parental substance use generally, create and implement a shared safety plan and identify mechanisms to establish inter-agency partnerships and future joint-working.

In terms of wider policy influencing, Adfam responded to the Department of Health’s invitation for feedback on its document, *Drug Misuse and Dependence: UK Guidelines on Clinical Practice*,²¹ detailing how children can be effectively safeguarded from the risks of OST medications, based on the recommendations of the report. A response was also submitted in 2015 to the CQC’s proposals for inspecting and rating providers of substance misuse services, highlighting the issues around child OST ingestion and necessary safeguarding implications.²²

²¹ Department of Health (2007) *Drug Misuse and Dependence: UK Guidelines on Clinical Practice*

²² Both responses are available to view on Adfam’s website

Conclusions & Recommendations

This report contributes to and further informs the ongoing debate on how to most effectively manage the risks to children posed by medications used in OST, whilst being mindful not to endanger the rightful place of OST in the treatment of opioid dependence. It has revealed that between 2003 and 2014, at least 328 children in England have been hospitalised with methadone poisoning, and in the UK at least 110 persons aged 18 and under have died from methadone (107) and buprenorphine poisoning (3) between 2003 and 2013. The data shows that the majority of ingestions involved adolescents, and further research into how and why adolescents ingest OST medications is warranted. There have been three more SCRs involving young children's ingestions of methadone, and recommendations centred on improving joint-working and information-sharing, and developing the workforce's skills and knowledge. Research evidence also suggests that methadone presents a higher mortality risk than buprenorphine, and more needs to be done to assess the relative benefits and risks of prescribing methadone and buprenorphine to parents in treatment.

The continuation of SCRs, hospitalisations and deaths, and the ad hoc nature of the actions taken in different local areas, emphasises the need for a nationally-driven, coordinated response to prevent future child ingestions of OST. It is encouraging to see that isolated actions are being taken to better children's safeguarding from the risks posed by these drugs, and it is hoped that

the examples of local practice provided in this report will encourage further progress towards this aim.

The original report identified a number of key issues, and this report has confirmed that they have mostly yet to be resolved. These issues together with the recommendations made in the original report (amended to reflect whether they have been followed up) are set out below, with new recommendations made in light of new evidence.

Issue 1: National learning from SCRs is lacking

Original Recommendation: Full overview reports of SCRs involving OST drugs should be centrally analysed by Government-appointed researchers. Further research into these cases and the learning from them is warranted. There should also be a commitment to collect and review any OST cases across the UK biennially and examine the key learning points for practitioners, the implementation of new recommendations and any lessons for good practice. The Department for Education or Ofsted would be best placed to carry out this work.

New Recommendation: These biennial analyses should be disseminated to relevant practitioners and organisations.

The Association of Independent Local Safeguarding Children Boards Chairs in England, and their national equivalents in Wales, NI and Scotland are in a prime position to collate and analyse reviews and disseminate learning to LSCBs.

Issue 2: The effectiveness of SCRs

Original Recommendation: A representative from a drug treatment agency should be present on all Local Safeguarding Children Boards. Drug treatment services should also be represented on the Review Panel for any Serious Case Reviews where the parents' drug or alcohol use is relevant.

Issue 3: A lack of publicly available information and data around the issue

Original Recommendation: Data should be collected centrally on the number of parents prescribed different OST drugs, and on which supervision regimes, analysing these cases to determine whether they involved accidental ingestion or intentional administration. Collection of this data should be the responsibility of Public Health England (PHE) or the Department of Health.

New Recommendation: Hospitalisation data and mortality statistics should be centrally monitored to identify emerging patterns and trends. This should be the responsibility of PHE or the Department of Health. More information on the circumstances surrounding the death should also be recorded. This data should be published biennially. The development of national standards for reporting child ingestions of OST medications and clarification on SCR thresholds is also warranted, and further research into the circumstances by which adolescents come to ingest OST drugs is needed. Research into how and why parents may be administering drugs to their children is urgently needed.

Issue 4: A lack of awareness of the dangers of OST to children and professional competency

Original Recommendation: Training for drug services, pharmacies and GPs must highlight the dangers of OST medicines to children. Workers should also be able to address the intentional administration of OST medicines and other drugs to children with service users and promote positive parenting practices. Other professionals working with vulnerable families, especially those undertaking home visits, need to be alert and vigilant about the dangers of OST drugs.

New Recommendation: Home visits should be regularly conducted, and the role of health visiting teams recognised by local partners. Health visitors should receive training and guidance on working with families where parental substance use is a factor. Routine notification procedures for professionals working with the family are conducive to effective information-sharing, early intervention and prevention. However, further research should be conducted to clarify issues of consent when sharing personal information. Drug services and commissioners should explicitly include a ‘child focus,’ in service level agreements and service specifications.

Issue 5: Despite clinical guidelines, safeguarding concerns are not sufficiently prioritised in reality

Original Recommendation: Guidance on the implementation of NICE, specifically Technology Appraisal 114, must reemphasise safeguarding children as a primary factor in decisions about OST, including which drug to prescribe and whether to permit take-home doses. This would be the responsibility of PHE or the Department of Health. There is also a role for the Secretary of State for Health in ensuring that NICE is implemented at the local level.

New Recommendation: Further research into the relative safety of buprenorphine and methadone specifically in the context of child ingestions is warranted. Clinical guidelines should clarify the circumstances under which both drugs will not be considered ‘equally suitable.’

Issue 6: We know that a single, isolated incident can be fatal. Safety measures should reflect this

Original Recommendation: Safe storage boxes should be provided to all treatment clients in receipt of OST, if they ever take any of their prescription home. There must be consistent checks on storage arrangements, and ongoing information about the dangers of OST. Systems should be in place between different local agencies to distribute knowledge of, and responsibility for, monitoring and ensuring safe storage.

New Recommendation: Further research and clarification of guidelines on the use of naloxone in cases of child ingestions is warranted.

This is an executive summary. The full report is available from www.adfam.org.uk.