A Toolkit for Recovery Advocates in England

MAKING OUR VOICES COUNT

Prevention works

Treatment is effective

Recovery from addiction is a lived reality in millions of people's lives

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By our Silence we let others define us

The Faces and Voices of Recovery UK is an advocacy charity which exists to save lives and improve health and wellbeing by challenging addiction related stigma and encouraging, empowering and educating people in recovery from addiction, their families and friends, and those who work with them. Our primary purpose is to spread the message that prevention works, treatment is effective, and recovery from addiction is a lived reality in millions of people's lives. As a public and professional education organisation we have produced this toolkit to support the work of those involved in local advocacy work for prevention, treatment and recovery support services in England and we hope you find it useful.

In the *Introduction* we describe what recovery advocacy is and the benefits that investing in effective prevention, treatment and recovery support services bring to society. In *How it works*we describe the landscape for prevention, treatment and recovery support services,the key organisations involved and how the funding works. We have focused on England because we believe that the need for effective recovery advocacy is more pressing in England as a direct result of the *Health and Social Care Act (2012).* In *Into action*we describe some practical steps you can take as a recovery advocate. While the landscape is different in Scotland and Northern Ireland, and to some extent in Wales, because of the *Health and Social Care Act (2012),* many of the general principles of recovery advocacy and practical actions outlined in this chapter can be applied in other areas of the UK. In the *Appendix* we have included links to a range of statistics that may be useful in local recovery advocacy work.

If you require more support with advocacy in your local area please don't hesitate to get in touch with us on info@facesandvoicesofrecoveryuk.org

Contents

1. Introduction

a) What is recovery advocacy?

The Oxford English dictionary defines advocacy as "public support for or recommendation of a particular cause or policy". Recovery advocacy simply means publicy supporting recovery from addiction to alcohol and other drugs. It can take different forms, for example working to improve local services so that everyone has every opportunity to recover, challenging disinvestment in services, supporting someone to get the treatment and support they need and challenging all forms of stigma that objectify and dehumanise people addicted to alcohol and other drugs.

People in long term recovery, along with their families and friends, are the visible, living proof that there are solutions to addiction to alcohol and other drugs. They can be powerful advocates when theytalk about their experience of recovery in public. They can help inspire people in addiction to try recovery for themselves and help educate the public and influence policy and decision makers. Similarly, people working in the field such as doctors, public health professionals, local government officers and civil servants can be powerful advocates, for example, by working to improve local services or arguing the case that investing in effective prevention, treatment and recovery support services brings many benefits to the whole of society. Anyone who supports recovery from addiction to alcohol and other drugs can, and should, be a recovery advocate.

There are also many people across the UK in 12-step recovery that may want to advocate for effective prevention, treatment and recovery services by speaking out about their own recovery experiences but may feel apprehensive because of the principle of anonymity. There is, however, a long and rich tradition of people in 12-step recovery speaking out as advocates. A leaflet and guide to how they can do this are available here:

www.facesandvoicesofrecoveryuk.org/wp-content/uploads/2013/11/Advocacy-with-Anonymity-Leaflet.doc

www.facesandvoicesofrecoveryuk.org/wp-content/uploads/2013/11/Advocacy-with-Anonymity-final-Templatev1-2-1.pdf

b) Why invest in services for alcohol and other drugs?

Addiction to alcohol and other drugs causes suffering, death and despair to those affected:

- 1.6 million adults show some signs of alcohol dependence
- 15,479 people died from alcohol-related causes in 2010, up 30% since 2001
- there are 299,000 heroin and crack users in England
- deaths among heroin users are 10 times the death rate in the general population
- 1,200,000 people are affected by drug addiction in their families, mostly in the poorest communities

Problematic use of alcohol and other drugs causes harm across the whole of society:

- alcohol is a factor in almost half of violent assaults
- 27% of serious case reviews mention alcohol misuse
- Alcohol is a factor in 17% of road fatalities
- parental drug use is a risk factor in 29% of all serious case reviews
- heroin and crack addiction causes crime and disrupts community safety, with a typical user spending around £1,400 per month on drugs

The economic costs to society are staggering. The annual cost of alcohol-related harm is approximately £23bn:

- crime in England - £11bn
- costs to NHS in England - £3.5bn
- costs related to lost productivity in UK - £7bn

The annual cost of addiction to other drugs to society is approximately £15.4bn:

- in 2011 the cost of deaths related to drug misuse was £2.4bn
- drug misuse costs the NHS in England £488m per year
- any heroin or crack user not in treatment commits crime costing an average of £28,074 per year
- looking after the children of drug using parents who have been taken into care costs £42.6m per year

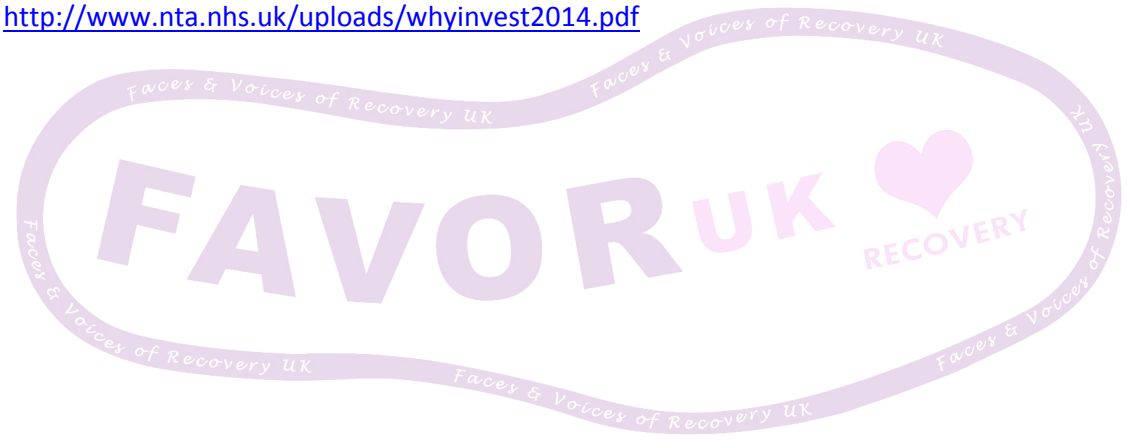
However, investing in services to prevent and treat problematic use and addiction to alcohol and other drugs and support recovery from addiction can bring enormous savings for society:

- alcohol and other drug interventions for young people result in £4.3m health savings and £100m crime savings per year

- alcohol and other drug interventions can help to get young people into employment, education and training, bringing a total lifetime benefit of up to £159m per year
- every £1 spent on alcohol and other drug interventions for young people brings a benefit of £5-8 for society
- one alcohol liaison nurse can prevent 97 A&E visits and 57 hospital admissions, saving the NHS £90,000
- treating 100 alcohol dependent people costs approximately £40,000 but saves the NHS £60,000 by preventing 18 A&E visits and 22 hospital admissions
- drug treatment prevents an estimated 4.9m crimes per year
- every £1 spent on drug treatment saves £2.50 in costs to society

Useful information on the costs to society of addiction and problematic use of alcohol and other drugs and the benefits to society of investing in prevention, treatment and recovery services can be found here:

http://www.nta.nhs.uk/uploads/whyinvest2014.pdf



2. How it Works

a) Responsibility for services for alcohol and other drugs

As a result of the*Health and Social Care Act (2012),* local authorities in England have, since 1 April 2013, been responsible for improving the health of their local population and for public health services including prevention, treatment and recovery support services for alcohol and other drugs. More information about the transfer of public health responsibilities to local authorities can be found here:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213009/Public-health-role-of-local-authorities-factsheet.pdf

The following public health functions and services have been *mandated*, in other words, they have to be provided by local authorities:

- NHS health check for the over 40s
- National Child Measurement Programme
- Some sexual health services
- Providing public health advice to local NHS Clinical Commissioning Groups
- Local health protection assurance functions

It remains unclear whether or not there remain any legal requirements for local authorities to ensure that prevention, treatment and recovery services for alcohol and other drugs are available in local areas in England.

b) Funding for services for alcohol and other drugs

Before April 2013 adult and young people's community drug treatment in England was partly funded by money from central government allocated to local areas, known as the ring fenced Pooled Treatment Budget while alcohol treatment was mostly funded by local areas themselves. Pooled Treatment Budget allocation to local areas in 2012/13 can be found here:

http://www.nta.nhs.uk/uploads/drugfunding12-13v.xls

Funding for prison treatment in England was made available through Health Authorities and a detailed breakdown of 2011/12 drugs and alcohol treatment funding for both adult prisons and children and young people's secure estates can be found here:

http://www.nta.nhs.uk/uploads/2011.3.31announcementofadultprisonsubstancemisusefunding.pdf

http://www.nta.nhs.uk/uploads/2011.03.31childrenyoungpeoplesubstancemisusefunding.pdf

Since April 2013 funding for public health services in England, including prevention, treatment and recovery services for alcohol and other drugs, is allocated to local authorities. Previously funding allocations to local areas for public health were based on levels of deprivation but are now based on premature mortality rates and this has been criticised for moving funding away from the most deprived areas. See for example, this Guardian article on *Unfair health funding*:

http://www.theguardian.com/society/2013/mar/19/jeremy-hunt-unfair-health-funding

This Public Health Grant for local areas is ring fenced for public health services and initiatives but some local authorities have used it to fund other services that they claim have an impact on the health of the local population. See, for example, this BBC article on *Councils diverting public health cash*:

http://www.bbc.co.uk/news/health-26753121

Historically spending on prevention, treatment and recovery services for alcohol and other drugs made up around a third of total public health spending in local areas. While local authorities do have to report back to the Department of Health how much they spend on alcohol, drugs and young people's substance misuse services, they are free to reduce the amount of funding for these services and instead increase funding for other public health services.

The report, *State of the Sector 2013* contains the findings from a survey of nearly 170 alcohol and drugs services from across England carried out by Drugscope. It found that 35% of alcohol and drugs services surveyed reported a decrease in funding and almost half reported that they were employing fewer frontline staff. Respondents also highlighted

significant problems in their ability to offer clients support to improve recovery capital, particularly employment, housing and mental and physical wellbeing. Full and summary copies of the report can be found here:

http://www.drugscope.org.uk/Resources/Drugscope/Documents/PDF/Policy/SOS2013_Main.pdf

http://www.drugscope.org.uk/Resources/Drugscope/Documents/PDF/Policy/SOS2013_Summary.pdf

c) Health and Wellbeing Boards

The Health and Social Care Act (2012) also established a duty for each local authority in England to form a Health and Wellbeing Board (HWB), bringing the local Director of Public Health together with other local partners to improve the health and wellbeing of the people in their area and reduce health inequalities. Drug scope's *State of the Sector 2013* report highlights that services for alcohol and other drugs have struggled to engage with their local HWB in many areas.

Each HWB is required to carry out a Joint Strategic Needs Assessment (JSNA) to identify priorities for their local area and publish a local Health and Wellbeing Strategy(HWS) setting out how these priorities will be addressed. Many local authorities have published their Health and Wellbeing Strategy online. Some do address alcohol related harms but fewer address drug related harms, particularly through effective treatment and recovery support services. An interactive map showing local priorities for HWBs is available here:

http://www.local.gov.uk/web/guest/health-and-wellbeing-boards/-/journal_content/56/10180/6111055/ARTICLE

By selecting a theme, the map will highlight all areas addressing related priorities.By selecting a single area on the map you can view a summary of the local priorities, and access links to the HWS and reports highlighting measures of health and wellbeing for that area.

d) Healthwatch

Local Healthwatch organisations were established as consumer champions acting on behalf of patients and service users, and have a statutory place on local HWB. Their primary purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf. Their work is led and coordinated by Healthwatch England. The responsibilities of local healthwatch organisations include:

- entering and viewing local services
- influencing what services are available locally by having a seat on the local HWB
- providing information and advice about local services
- passing information and recommendations to the Care Quality Commission
- challenging providers and commissioners to ensure that their complaints system are open, transparent and easy to access

More information about Healthwatch can be found here:

http://www.healthwatch.co.uk

e) Public Health England

In April 2013 a government agency, Public Health England (PHE), was formed to provide evidence, advice and support to local authorities in fulfilling their new public health responsibilities. PHE was established as an executive agency of the Department of Health to bring together public health specialists from more than 70 organisations, including the National Treatment Agency and the Health Protection Agency, into a single public health service. PHE's Business Plan for 2014/15 is available here:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/319696/Business_plan_11_June_pdf.pdf

The Plan describes PHE's ambition to increase the publics' life expectancy and years of healthy life by focussing on a small number of priorities, including alcohol (along with tobacco, obesity, tuberculosis, dementia and every child having the best start in life). It also highlights PHE's shared ambition with local authorities to "improve recovery rates from drug dependency, recognising this as the core purpose of drug treatment". It will achieve this through intelligence, evidence and other forms of support, focussing on the most challenged areas.

f) Public Health Outcomes Framework

The Public Health Outcomes Framework sets out the key indicators the Department of Health expects local authorities to work towards. Information about the overall framework is available here:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216159/dh_132362.pdf

The framework contains the following indicators:

- 2.15i -% of opiate drug users that completed treatment successfully and did not re-present to treatment within 6 months
- 2.15ii - % of non-opiate drug users that completed treatment successfully and did not re-present to treatment within 6 months
- 2.18 – the rate of alcohol related hospital admissions

The performance of local areas against these three indicators can be viewed here:

http://www.phoutcomes.info/public-health-outcomes-framework#gid/1000042/par/E12000004

g) Re-tendering of services

Local authorities have a legal duty to ensure good value for the tax payers'money they spend and and to apply relevant UK and EU regulations such as the *Public Contracts Regulations (2006)*. This means that every few years local treatment and recovery support services may be "re-tendered". When the current contract is coming to an end, organisations are invited to submit a bid if they want to win the new contract to provide treatment and recovery support services, which are described in the *service specifications*. A new contract is awarded by a panel to the organisation that can provide the best quality service at the lowest price. This is also an opportunity to redesign services to improve outcomes and cost-effectiveness, but unfortunately can also provide an opportunity for local authorities to invest less money and reduce the range of services available.

3. Into Action

a) Making your voice heard

Over the past 20 years several major pieces of legislation have made service user involvement a requirement in health and social care services. The first of these was the *National Health Service and Community Care Act (1990)*, which made consultation with service users a legalduty for local authorities. The requirement for active service user (and carer) involvement in service development were strengthened in government directives on Best Value for local authorities, and the legislation associated with the public service 'modernisation'.

There is an important difference between involvement in improving your own service(s) and involvement at a wider "strategic" level in the planning and development of services. A key-worker or service manager will be able to tell you how you can be more involved in improving the services that you use, for example, collecting information from surveys and suggestion boxes and meeting with service managers to discuss possible improvements.If you have used treatment services, or know someone else who has, you can give feedback using Patient Opinion, which is an independent site about your experiences of UK health services, good or bad and is completely independent from the NHS. Everything you write is anonymous. You can see the most recent posts about substance misuse services and post directly onto Patient Opinion from this page:

http://www.nta.nhs.uk/patient-opinion.aspx

In many areas there is already a service user involvement/peer support organisation working at the "strategic" level, representing people who use treatment and recovery support services in planning and service development. The most effective way to make your voice heard would be to become actively involved with this organisation, possibly as a volunteer. A key-worker or service manager will be able to provide details of the organisation in your areas if there is one. HWBs have a legal duty to involve local people in the writing their JSNA and HWS. Each local authority area will approach this differently butit can be an important route for local organisations representing people using treatment and recovery support servicesto engage with the HWB. This can be a powerful way to influence the decisionmaking processes that will ultimately set local priorities.

To successfully influence JSNAs and HWSs, another good starting point is to contact the Council for Voluntary Service (CVS) in your area or its localequivalent. They will be able to describe how the JSNA process works and who the relevant contacts are. Also the local CVS often collates information from small organisations, such as those representing people using treatment and recovery support services, to present to those writing JSNAs, presenting the information with 'one voice' and reducing the amount work involved for organisations. To support those involved in this work, Public Health England have produced good practice guides for planning alcohol and drugs prevention, treatment and recovery services for adults and specialist substance misuse interventions for young people, and they are available here:

http://www.nta.nhs.uk/uploads/goodpracticeinplanningforalcoholanddrugspreventiontreatmentandrecovery%5B0%5D.pdf

http://www.nta.nhs.uk/uploads/goodpracticeinplanningyoungpeoplesspecialistsubstancemisuseinterventions%5B0%5D.pdf

If this is not successful then you will need to find contact details by searching online (search for "Health and Wellbeing Board" plus the name of your local authority, county council or metropolitan borough) or call your local council and ask. It may be useful to ask the following questions:

- Who is on the HWB?
- Will the public have any say over who is on the HWB?
- What stage is the HWS at? Can you see it? If not, why not?
- What is the HWB doing to involve the public in the development of the HWS at a formative stage?
- Can you attend their meetings as a member ofthe public, and see their minutes? If not, why not?
- How is the HWB accountable to the council as a whole – does it report formally to the Scrutiny committee or to full council? When? Can you have copiesof the reports?

If you are not satisfied that your HWB is going to be properly held to account and that the HWS does not consider the needs of people addicted to alcohol and other drugs and people in recovery from addiction, then you will need to contact the local Director of Public Health directly. A list of local Directors of Public Health is available here:

https://www.gov.uk/government/publications/directors-of-public-health-in-england--2

Healthwatch could also be an important vehicle for ensuring service users have a say in the local design, commissioning and delivery of treatment and recovery support services, and in promoting their rights. However, it represents service users across a wide spectrum of

health servicesbutit should give priority to those who often go unheard or come from excluded communities. People recovering from addiction to alcohol and other drugs will need to be very proactive to ensure that their voice is helping to shape the Healthwatch agenda, both nationally and locally. Details of local Healthwatch organisations can be found here:

http://www.healthwatch.co.uk/find-local-healthwatch

b) Families and carers

Having a relative or friend who is addicted to alcohol or other drugs is an extremelystressful and can affect a person's physical and mental health, finances, social life, and relationships with others. This often mean that families other carers need help in their own right, to enable them to cope better with what are usually ongoing, long-term issues. Also,including family members and carers in the treatment process often allows them to better support the person addicted to alcohol or other drugs. There is a good evidence to suggest that supporting and involving family members and carers effectively can lead to improved outcomes for family members and carers, as well as the person addicted to alcohol or other drugs and people in early recovery are also less likely to suffer a relapse.

National policy and guidance increasingly highlights the benefits of health and social care services involving and supporting carers. In June 2008, the Government published *Carers at the Heart of 21st Century Families and Communities* which set out the vision for developing support for carers over the next ten years. Effective support for family members and carers in their own right, and involvement of families and carers in drug users treatment can be achieved by the active involvement of family members and carers in the planning and commissioning of drug treatment, and family and carer services. Useful guidance on involving families and carers in treatment and developing services specific to families and carers is available here:

http://www.nta.nhs.uk/uploads/supporting_and_involving_carers2008_0509.pdf

c) Re-tendering and the duty to consult

Re-tendering can be an effective way of promoting innovation, increasing the accountability of services, redesigning services and in many areas it has enabled services to more effectively meet local needs. Consultation with service users and their families is vital when designing a treatment and recovery support system and in writing service specifications. Information about intentions to re-tender are usually found on local authority webites. Service users and their families have a unique perspective on current services and are often in contact with a large number of otherserviceusers and other people addicted to alcohol and other drugs not currently using treatment and recovery support services. Re-tendering provides an ideal opportunity to influence how local services should look and introduce some innovation.

Re-tendering can also be a complex process which should be properly managed through good communication, collaboration and consultation. The process can cause anxiety for service users, their families and the community. Local advocates should ensure that local commissioners understand the need to provide service users and their families with information about how any changes will affect them, to listen and respond to their feedback and provide regular updates. If myths and rumours are circulating, clarifications should be issued quickly and new and old service providers should hold workshops with service users and their families to explore their anxieties and explain the reality. The transition process should also be properly managed to ensure that there is no disruption of services.

It is important that local advocates and advocacy groups are informed of the intention to tender from the outset. They should be involved at every stage of the tender process and some examples are described below:

- Needs assessment – gathering opinions from a variety of sources
- Developing the new service model/service specifications – providing specialist expertise, identifying what works and what needs changing
- *Pre-Qualifying Questionnaire* and *Invitation to Tender*– contributing to devising the selection questions / scoring criteria and preparing an 'expert' interview panel of service user and family representatives
- Interview and evaluation – making site visits to shortlisted providers and collating feedback on whether the proposals are realistic, viable and achievable
- Hand-over and transition - supporting service users and families through the period of change and acting as a conduit for information, for example client consent / data sharing protocols

- Review – collating anecdotal stories, complaints and formal feedback to monitor and review the progress of the new service(s)

Unfortunately the re-tendering process can also be used as an opportunity to disinvest in local services, particularly expensive ones such as residential rehabilitation. ocal advocates should attempt to obtain as much financial information as possible. Sometimes this information may be "commercially sensitive" and will not be made available but information in the proposed service specifications will indicate if some services are going to be withdrawn. If you wish to challenge a local decision to disinvest in some services the best starting point will be a discussion with your local councillor or your Member of Parliament (MP). You can find details of your local MP here and how to contact them here:

http://www.parliament.uk/mps-lords-and-offices/mps/

http://www.parliament.uk/about/contacting/mp/

d) Freedom of Information Requests

If you are going to challenge disinvestment in treatment and recovery support services in your local area (or nationally) you will need accurate financial information. Under the *Freedom of Information Act (2000)* you have a right to access information held by public authorities such as local councils and the NHS. The Act covers any recorded information that is held by a public authority in England, Wales and Northern Ireland, and by UK-wide public authorities based in Scotland. Information held by Scottish public authorities is covered by Scotland's own *Freedom of Information (Scotland) Act 2002*.

You should identify the information you want as clearly as possible and your request can be in the form of a question, rather than a request for specific documents. Some information may not be given to you because it is exempt, for example, "commercially sensitive" information during a re-tendering process. The easiest way to make a request under the *Freedom of Information Act (2000*) is through the website available here:

https://www.whatdotheyknow.com/

Appendix

Annual publications from drug and alcohol treatment in England

The National Drug Treatment Monitoring System (NDTMS) and National Alcohol Treatment Monitoring System (NATMS) record information about people receiving structured treatment for drug and alcohol misuse in England (i.e. structured community-based services or residential inpatient services), in order to monitor progress towards the Government's targets for participation in drug treatment programmes. Annual reports for adult drug treatment, adult alcohol treatment and young people's substance misuse treatment are available here:

https://www.ndtms.net/Publications/AnnualReports.aspx

Prevalence of drug use

Estimates of the prevalence of crack cocaine and heroin use are produced for each local authority area in England. Estimates are available for 2006-07, 2008-09, 2009-10, 2010-11 and 2011-12. The estimates are produced through a mixture of capture-recapture and Multiple Indicator Methodology (MIM), and rely on NDTMS data being matched against and/or analysed alongside Probation and Home Office data sets. The data and further information are available here:

http://www.nta.nhs.uk/facts-prevalence.aspx

An additional annual estimate of the prevalence of drug use is undertaken through the Crime Survey for England and Wales (CSEW, formerly the British Crime Survey (BCS)). This section of the survey has been in place since 1996, annually since 2001, and has tracked the prevalence of the use of different drugs over this time:

https://www.gov.uk/government/publications/drug-misuse-findings-from-the-2012-to-2013-csew

Young people

Information is also available relating to the prevalence of drug use among secondary school pupils aged 11 to 15 from the Smoking, Drinking and Drug Use Survey among young people in England. This is a survey carried out for the NHS Information Centre by the National Centre for Social Research and the National Foundation for Educational Research. The

survey annually interviews school pupils, and has been in place since 2001. The data and further information are available here:

https://catalogue.ic.nhs.uk/publications/public-health/surveys/smok-drin-drug-youn-peop-eng-2012/smok-drin-drug-youn-peop-eng-2012-repo.pdf

International comparisons

The European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) publish an annual report that describes and compares aspects of drug use and drug policy within European states, as well as providing detailed comparative statistics. This can be found here:

http://www.emcdda.europa.eu/publications/annual-report/2012

Drug related deaths

The Office for National Statistics publish an annual summary of all deaths related to drug poisoning (involving both legal and illegal drugs) and drug misuse (involving illegal drugs) in England and Wales. This can be found here:

http://www.ons.gov.uk/ons/rel/subnational-health3/deaths-related-to-drug-poisoning/england-and-wales---2013/stb---deaths-related-to-drug-poisoning-in-england-and-wales--2013.html