drugsfutures

Public engagement on the future of brain science, addiction and drugs

Report for the Academy of Medical Sciences

May 2007

OPM®

Contents

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Summary

Funded by the Department of Trade and Industry's Sciencewise programme, the *drugsfutures* programme has been designed, delivered and managed by a consortium of organisations led by the Office for Public Management (OPM). The aim of *drugsfutures* was to explore the hopes and concerns of a broad cross-section of the public on current and future issues relating to brain science, addiction and drugs.

The Academy of Medical Sciences Working Group will consider the findings from the *drugsfutures* programme before publishing a final report at the end of 2007, which will include recommendations for future research and public policy. The Government is expected to give a written response within 18 months of the report's publication.

OPM managed the project and the other consortium members were Dialogue by Design, Martin Ince, Think-Lab, the BA, the IPPR, the Dana Centre, the European Dana Alliance for the Brain and Diane Warburton.

Consultation scope and process

Three classes of drugs and five themes determined the parameters of the project. The three classes of drugs were:

- Recreational drugs
- Medicines for mental health
- Cognition enhancers.

The five themes were:

- Drugs and the law
- Drugs and society
- Drugs for a smarter brain
- Drugs and young people
- Drugs and mental health

Face-to-face activities took place between 31st January and 31st March 2007. An on-line consultation ran between 31st January and 2nd April. The total number of participants in this project was 727. Participants ranged in age from 13 (in Belfast) to 96 (in Merthyr Tydfil). A detailed breakdown of the sample is provided in the Appendix to this report.

Face-to-face activities were:

- A launch event held in the Dana Centre, involving the general public, policy-makers and scientists
- A reconvened deliberative workshop, taking place over 3.5 days in total, with a 1.5 day introductory session at the start of the project and a 2-day session at the end of the project;
- Five regional one-day workshops, each of which was organised around a specific theme;
- Smaller 'outreach' workshops with specific groups

The on-line element comprised a blog and a structured consultation. The same materials were used in face-to-face events and on-line.

Main findings

A detailed analysis of people's views on each of the three substance types can be found in the report. The main findings, however, are summarised in the hopes and concerns that people expressed. These describe two broad futures, and although not every element of these was subscribed to by all participants, they do serve to provide an overall picture of the majority's hopes and concerns, and their priorities for achieving the positive future they envisage.

One possible future is dystopian, developing out of what participants think is wrong with our current attitudes and approaches to mental health problems, mental health drugs and recreational drugs, and their concerns about cognition enhancers. The main features of this negative future are:

- Mental illness and addiction are stigmatised and largely invisible
- The use of licit and illicit recreational drugs continues to increase
- There is general reliance on the fastest, probably pharmaceutical, solution to mental health problems
- Society is infatuated by competition in education and employment, with cognition enhancers used to gain advantage in the race for success
- The definition of a mental illness includes things such as shyness
- There is heavy spending by pharmaceutical companies on marketing drugs for shyness and other characteristics that make people stand out as being different
- Babies are tested in the womb for predisposition to addiction; some with this predisposition are aborted before birth
- Drugs are used to control older people and those with mental health problems, rather than to treat them
- Research investment is focused on the development of drugs to treat conditions but little is spent on understanding their origins and preventing their occurrence
- The prisons are overflowing with addicts and adults with ADHD.

The other possible future is more positive and its most notable difference from the negative picture above is a change in attitudes towards drugs, their role in society and healthcare and towards those who use them. The main features of the positive future are:

- There is no stigma attached to mental health problems, drug use or addiction
- Drugs are only one of many ways of treating mental health problems and the other approaches are widely available and of high quality
- Research has led to the development of drugs for mental illness that have minimal side effects and are prescribed only when necessary
- Expecting recreational drug use to disappear is seen as unrealistic
- Health, rather than punishment, is the framework for supporting those whose use becomes a problem, and the services are widely available and of high quality
- Primary care and community health workers are as experienced in working with addicts and people with mental health problems as they are in helping someone with a broken leg.
- All children receive age-appropriate, effective education on drugs of all types and on the issues that play a role in decisions about their use. Users and ex-users are widely involved in the design and delivery of drugs education
- Only those users who commit crimes wind up in prison.The penalties for larger dealers are harsh and are applied without question.
- Research on the causes of Alzheimer's Disease and schizophrenia has given scientists a good understanding of their causes
- Doctors and patients work together, with families and carers where necessary and beneficial, to work out the best course to take.

How drugs currently classed as 'illicit recreational' should be distributed in this positive future remains unclear. Three possibilities were raised:

- They can be bought through not-for-profit outlets, in restricted quantities. Purity is assured and the crime and violence associated with the black market are greatly reduced
- Only some are available in this way, such as cannabis, with the harder drugs remaining illegal
- The classification system has been redrawn on the basis of research into the individual and social harms associated with the use of the various substances. All currently illicit drugs remain controlled and available only on the black market.

A final hope is that public views are seen as integral part of decisions taken on these issues.

1. Introduction

Background to the project

Towards the end of 2005, the Government invited the Academy of Medical Sciences to undertake an independent review of the issues raised in the Foresight report, *'Drugs Futures 2025?'.* Informed by 15 'state-of-the science' reviews, the Foresight project explored the likely impact of advances in the sciences and social sciences in relation to: legal and illegal 'recreational' drugs; medicines for mental health; and 'cognition enhancers'. The project findings appeared in July 2005 with the launch of *Drugs Futures 2025?*

The Academy convened an expert Working Group, chaired by Sir Gabriel Horn FRS, to take this study forward. The remit of the Working Group is to:

- consider, in consultation with experts and the public, the societal, health, safety and environmental issues raised by *'Drugs Futures 2025?'*
- report back to the Department of Health and other Government stakeholder departments with recommendations for public policy and research needs.
- in the course of the consultation, address the Government's policy priorities in this area.

The membership of the Working Group, including both Academy fellows and external experts, reflects the diversity of the issues to be explored and includes experts in epidemiology, medicine, neuroscience, psychiatry, pharmacology, philosophy, psychology and law.

To ensure that the final recommendations of the Working Group are relevant and informed by both scientific evidence and public concerns and aspirations, the Academy commissioned a national programme of public engagement activities (entitled *drugsfutures*). Funded by the Department of Trade and Industry's Sciencewise programme, the *drugsfutures* programme has been designed, delivered and managed by a consortium of organisations led by the Office for Public Management (OPM). The programme of public engagement explored the hopes and concerns of a broad cross-section of the public on current and future issues relating to brain science, addiction and drugs.

The Academy Working Group will consider the findings from the *drugsfutures* programme before publishing a final report at the end of 2007, which will include recommendations for future research and public policy. The Government is expected to give a written response within 18 months of the report's publication.

A note on public engagement

Public engagement is not research. Whilst it may borrow some tools from research – for example, in recruitment – its primary function is engage people in dialogue and debate. Unlike research, public engagement is not method driven. The most effective approach to a project will depend on factors such as who is to be engaged, what the topic is, the budget and timescale, the likelihood of conflict, the presence or absence of special interest groups, the involvement of experts and policy-makers and the nature of their involvement, and the reasons for wanting to undertake the engagement project in the first place. The Wellcome Trust's booklet, *Engaging Science*, says the following about public engagement:

> *'[P]ublic engagement remains an amorphous entity; it does not have any widely agreed coherence. As a term, it means different things to different people. For some, it refers just to 'dialogue', where there is genuine discussion between scientists and the public; for others, it is about the importance of the public voice being fed into scientific policy making; for others still, it covers the full panoply of activities in which scientifically trained or active individuals interact in some way with people or groups without a scientific background.'*[1]

The creation of knowledge, which is integral to research, is also important in public engagement. However, other things are also important, notably the perceptions amongst those involved of the likelihood and nature of any action which might be taken on the basis of the knowledge created. There is a 'promise' made to participants in a public engagement project, whether implicit or explicit, which is that their priorities or recommendations will be given serious consideration. If these are not acted upon or included within a wider set of recommendations, the reasons need to be explained to those who took part. This is not a promise made by research.

Public engagement is often seen within the context of participatory democracy. In that sense it is about power and politics, people's relationship with the state and the extent to which they feel their views as citizens are valued and accorded weight by the state, its agents or other public bodies. Understood in this context, it is a process developed by those who are involved. The process *is* the involvement. It ensures that different voices are heard and allows them to participate as fully as they want to, in ways that suit them. Participants determine the relevant questions around a particular topic, how these should be asked and what information they need to to help them answer the questions. They might determine what the topic is in the first place.

The implications of this end of the public engagement spectrum for commissioning and funding organisations and for those who practise public engagement are wide-reaching and too complex to consider here. And this project does not visit this far end of the spectrum. However, these comments might serve to reinforce our understanding of the amorphous nature of public engagement, which may be so not because a desired coherence has not

1 Matterson, C 2006, Engaging Science: Creative enterprise or controlled endeavour? In Jon Turney (Editor) *Engaging Science: Thoughts, Deeds, Analysis and Action*, Wellcome Trust 2006, p4

been agreed but because to pin it down would be to prefer organisational method over public process.

This project included some dialogue between scientists and the public, both directly, where experts attended events, and indirectly, through the input of the Academy of Medical Sciences Brain Science, Addiction and Drugs Working Group into its aims, scope and process. It presented a unique problem, as does every project. The particular policy area, the timescales over which the policy-making process will unfold, any sensitivities attached to the issue or to the relationship any particular groups have to the issue and more practical concerns such as those noted above, all need to be taken into account in the planning stages.

drugsfutures and Drugs Futures 2025

This section comments briefly on how the findings from *drugsfutures* compare with those emerging from the previous public engagement work done on the same topics, as part of the Foresight project on brain science, addiction and drugs, reported as *Drug Futures 2025.*[2] That project, carried out exactly two years earlier than *drugsfutures,* was also managed by OPM and included workshops and discussion groups, but not, as in the 2007 version, an on-line consultation.

The earlier consultation involved members of the general public, children with ADHD and their carers, users of illicit drugs, and young people in school years 9 to 13. They were asked about their views on mental health drugs, mood-altering drugs, pleasure drugs and cognition enhancers.

The work showed that the public, including the special interest groups, was generally supportive of drug innovation but had a fear of science 'going too far,' for example with developments in genetics and nanotechnology. On the issues specifically raised in this consultation, people tended to prefer options that enhance individual choice, including the right to use drugs, while agreeing that the vulnerable need to be protected. They expressed hostility towards new drugs that might 'normalise' society and reduce tolerance for creativity and eccentricity. Both illicit drug users and people who had cared for ADHD patients were sympathetic to people self-medicating, even with illicit drugs.

Contrast between the two projects

Content

Both projects involved individuals with both direct and general knowledge of licit and illicit drug use: the 2007 work included people with mental health problems, parents of children with ADHD and young people. Both projects looked at drugs for mental health, for recreation and for cognition enhancement.

In both projects, people agreed that individuals should have the right to use a drug they feel they need for a specific problem. But they were very concerned that drugs are being used too easily as a quick fix for mental health problems. This applies especially to new drugs for

2 The full report of this research is available at www.foresight.gov.uk.

conditions such as shyness where, people felt, non-drug therapies should be tried before drugs come into play. The concern that difference is a valuable aspect of society and is threatened by the medicalisation of conditions that are part of normal human variation emerges from both studies.

Both these pieces of work reveal a high level of awareness that illicit and licit so-called 'recreational' drugs are associated with harm to individual users, those around them, and society at large. The 2007 project shows greater emphasis on the harms associated with alcohol, and an awareness that smoking is becoming far less acceptable than in the past.

In both projects, people's views on cognition enhancement were that suitable drugs might be a positive development for the old and for dementia sufferers, two overlapping but not identical groups. However, they also thought that such drugs should only be used as part of a more general care regime, and only with care. There was also some agreement that cognition enhancement might be positive for people, such as pilots, working in safety-critical jobs.

The 2007 project participants saw substantial problems with the wider use of cognition enhancers, such as the devaluation of 'normal' achievement, pressure to use drugs, and the possibility (reflecting other concerns expressed during the consultation) that drugs might be used to control people and society in general. However, people tended to agree that individuals have the right to make decisions for themselves in this area, but argued that a great deal more research needs to be done on the safety of this class of drugs before policy on their use can be made.

The earlier project did not focus specifically on drugs and young people. But it did reveal a wide range of attitudes to drug use among the young, ranging from support for complete legalisation to puzzlement as to why people might wish to use drugs. The 2007 participants called for more support and education to help possible young drug users, for example those subject to peer pressure or with some other susceptibility to drug use. They seemed in general to take a more informed view of the issues. For example, they were conscious that singling out individuals who need such support also risks stigmatising them. The message from some of the young people in the 2007 project was that taking drugs is not cool: they were clear about disliking the effects on their friends of ongoing drug use.

In general, these two reports agree that members of the public take a subtle view of drug use, and are aware that measures to prevent drug use can attack individual freedom and discretion. They show that people are aware of the possible misuse of drugs for social control, and of their potential for over-use as an easy option for the medical and caring professions. But on the basis of these findings, awareness of possible drug harm may also have grown between 2005 and 2007. This applies to alcohol but also to the main illicit drugs.

Process

In making comparison between the 2005 work and *drugsfutures*¸ it may also be worth looking at how the issues were presented in both the materials used by participants and in the language used. In the 2005 project, each workshop used the same materials, including the agenda. This meant that all participants looked at the three classes of drug within a similar framework. In the 2007 work, each workshop covered a different theme. This approach meant that the same issues arose in different workshops but the perspective on these was shaped by the particular themes and questions asked. This has led to additional richness in the findings from 2007 and a more complex debate. It illustrates, too, how important it is to consider how the design of a project can affect the findings.

In the 2005 work, the term 'psychoactive substance' was preferred over 'drugs', because the general public tends to use the term drugs primarily for illicit 'recreational' drugs. However, using an unfamiliar term such as 'psychoactive substance' brings its own difficulties and these are outlined in the 2005 report, *Public Perspectives*.

drugsfutures was also a much larger project. The Foresight work involved 87 public participants; *drugsfutures* has involved 727 participants, over 500 of whom were involved directly, either online or face-to-face. Because the public engagement work was planned into the Academy's thinking from the start, the two strands – expert and public – were also very well-integrated. Working group members were involved in framing the questions to be asked: they attended events and were provided with regular updates on progress. The Working Group has made a commitment to consider the findings from the public engagement activities when developing the recommendations it will make in its report to the Department of Health at the end of 2007.

The findings

The people who took part in *drugsfutures* came from a wide range of backgrounds. They brought with them different experiences of drug use and mental health problems and different attitudes to the issues discussed. As is often the case when the findings of public engagement work are analysed, there will be some views, expressed by only a very few participants, that are not covered in the report. If a reader of this report who also took part in the project finds that views they expressed, or heard expressed, are not reflected, this should not be taken to suggest that these views are not important. We have tried to cover as many of the different positions taken as possible (hence the length of the report) but inevitably, some will not have been captured here.

How this report is organised

There will inevitably be some repetition in this report. Many valid points recurred under different themes or in discussion of the different classes of drugs. Rather than seeking to eliminate this, we have decided that it serves to reinforce those issues that were raised repeatedly.

The findings are organised under the following chapter headings, that are largely self-explanatory:

- Methodology
- Launch event
- Common themes
- Drugs for mental health
- Recreational drugs
- Cognition enhancers
- Drugs and young people
- Control and regulation
- Cross-cutting issues
- The future.

2. Methodology

Working in a consortium

This project was delivered by a consortium. In addition to the undoubted value of bringing together people with different skills, knowledge and perspectives, working in this way widened understanding amongst the members of the consortium of the process in which they were involved. Early discussions to agree our overall approach and to ensure shared aims and a common language were crucial.

It was also important that we understood differences in the ways we worked and the expectations we might have of each other. Different ways of engaging people raised new questions; and we needed to consider, too, how the face-to-face work and the on-line work would sit together. The nature of on-line consultation generally meant that many of the on-line participants represented organisations that had some existing relationship with the subject. This raised questions for the analysis of findings: the project was primarily about public engagement, so it was necessary to consider how to position the organisational responses in relation to those of the public. Given the similarity of responses from on-line and face-to-face participants, the decision was taken to integrate them and to indicate in the text any differences in opinion between the two channels.

Using the media to help us meet our own aims was also a challenge. Local media were often enthusiastic about covering regional events, but national media were looking for a story. The fact that a consultation is occurring is not news. Their interest was properly aroused only when findings began to emerge towards the end of the project. Pieces on cognition enhancers, for example, appeared only after the close of the on-line consultation and the final public engagement event. Since one aim of the media coverage was to drive traffic to the project website, there was some frustration about this. However, the project or the topics discussed did receive local radio, print and TV coverage, national print and radio coverage, and international print coverage. Details of this can be found in the appendix.

The Dana Centre, which organised and hosted the launch, had a format for events, which needed adapting to suit the aims of this project. For example, a good proportion of participants were recruited to attend, rather than signing up through the Dana Centre website. This meant that the audience profile differed from the one that might normally be found at this kind of event at this kind of venue.

Extended discussion groups were held, with note-takers, to ensure that we got some early insight into the participants' range of views. This was a further departure from the Dana Centre's more usual format, moving it a little in the direction of 'public engagement', though not sufficiently far to warrant the term 'deliberation'. From the Dana Centre's perspective, this approach required more staff than they might usually use, and very tight control on the night to ensure the process ran smoothly. EDAB's success in enlisting the support of many of the scientists who attended the launch contributed to its overall success too, and in particular, to that of the round table discussions.

The consortium members are:

- **OPM** – **lead member –** client contact, process design, design and production of content, face-to-face consultation, analysis and reporting, project management, quality assurance
- **Dialogue by Design –** process design, e-consultation, analysis and reporting
- **Martin Ince –** project science writer / adviser, supporting production of content
- **Think-Lab –** media and marketing
- **BA** – helping to organise launch event; facilitating outreach work
- **IPPR** – policy advice / support with media contacts
- **Dana Centre** – publicising, helping to organise and hosting launch event
- **EDAB** – access to network of European neuroscientists
- **Diane Warburton** – independent evaluation

Scope of project

Three classes of drugs and four themes determined the parameters of the project. The three classes of drugs were:

- Recreational drugs
- Medicines for mental health
- Cognition enhancers.

The four primary themes identified and prioritised by the Academy Working Group were:

- Control and regulation of drugs
- Attitudes towards drugs use
- Young people and parents
- Addiction and mental health treatments.

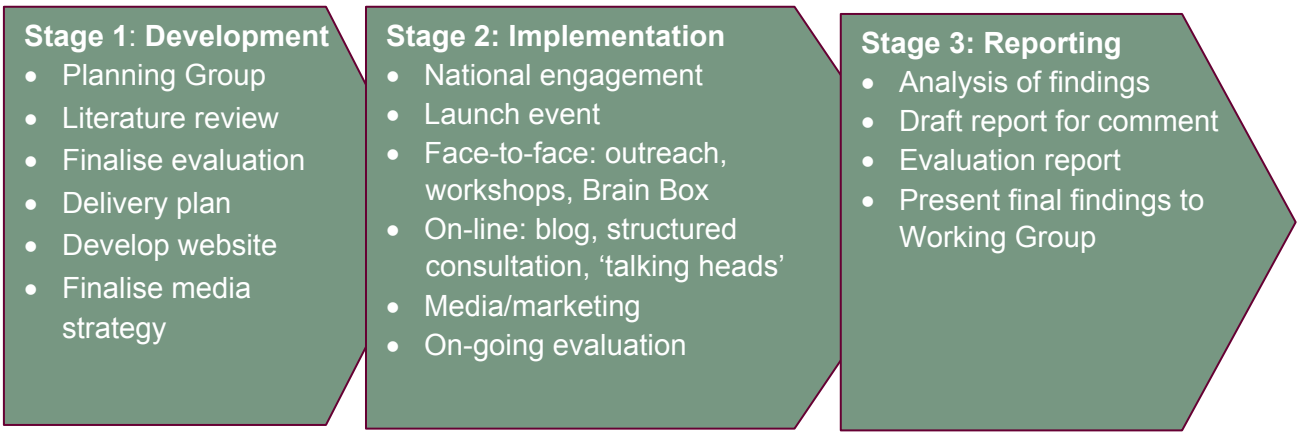
During the planning stage, we decided that the following five themes should structure the process:

- Drugs and the law
- Drugs and society
- Drugs for a smarter brain
- Drugs and young people
- Drugs and mental health

Structuring the content in this way meant that the same drug type could be approached from different perspectives and similar issues explored in different contexts. For example, 'recreational drugs' could be included in discussions of the law, society, young people and mental health; and mental health drugs could be discussed in terms of their role within society and in relation to their use by young people, as well as in the workshop focused on mental health.

Approach

The following diagram provides an overview of the approach:



Outline of project stages

Stage 1: Development

Literature review

The objective of the literature review was to look at *public engagement* projects on brain science, addiction, and the three classes of drugs central to *drugsfutures*: cognition enhancers, drugs for mental health and recreational drugs. The public involved in the project raised a far greater range of issues, as can be seen from this report. If the literature review had ranged over these issues too, there would no doubt be additional comparisons to be made between this work and previous projects.

A number of research projects and inquiries have covered some of the issues addressed in this project. For example, MORI ran a poll on Attitudes to Illegal Drugs, done on behalf of the Police Foundation and reported on in March 2000. A MORI poll conducted for the Fawcett Society, reported on in April 2004, showed high levels of public support for offering women offenders drug treatment, mental health care and community sentences rather putting them in prison. In June 2004, the Joseph Rowntree Foundation published *Drugs Testing in the Workplace,* its report on the findings of an independent inquiry facilitated by DrugScope and funded by the Joseph Rowntree Foundation and the Network of European Foundations. *Drugsfutures* explored this issue in discussions about cognition enhancers.

These reports and others will be of interest to anyone seeking to understand the views held about drugs by the public and by experts from a variety of backgrounds. However, they are not public engagement projects and so were not included in the Literature Review. Instead,

the review addressed work such as the Meeting of Minds, the European Citizens' Deliberation on Brain Science. This project involved 14 members of the public from 9 European nations, including the UK, in discussion on the most important societal issues arising from brain sciences. This is one of only very few projects that engages the public in dialogue on these issues. Another is the Foresight project on Brain Science, Addiction and Drugs, the forerunner to the Academy of Medical Sciences own work with that title.

The report on the literature review is provided separately. The following provides a broad overview of some of the key issues.

Drugs for mental health

Public engagement work on attitudes to drugs and mental health is limited. Research reports such as those from the Sainsbury Centre for Mental Health highlighted the stigma that is still attached to people with mental illness. This was also emphasised in *drugsfutures.* The potential futures of drugs for mental health were not explored in any of the reports found in this review.

Drugs and young people

There is wide awareness of the use of drugs such as methylphenidate, usually known under its trade name Ritalin. This is largely a result of debate in the media about the nature of Attention Deficient Hyperactivity Disorder (ADHD), the benefits and disadvantages of using drugs such as Ritalin to control the condition, and the rise in the diagnoses of ADHD. We found no public engagement projects looking at the acceptability of this form of cognitive enhancement.

Public engagement work has been done on young people's use of recreational drugs. We would expect that in addition to more formal and structured projects, a lot of small-scale projects have been done that do not result in a report. In line with our own work, previous findings include concern over rising drug use, the effect of cannabis on the young mind and brain, the growing strength of 'soft' drugs and the potential for them to act as a gateway to harder drugs.

Drugs and the law

Public engagement projects focused on the regulation and control of recreational drug use are limited. Perceptions of how the public views the current classification system appear to be based primarily on media opinion pieces rather than on larger studies of public opinion.

One report which builds in some public perception work is the '*Perspectives on Cannabis Conference 2002'* report. The public engagement element of this event was limited to public attendance and a question and answer session allowing some interaction between 'experts' and the public. Other reports from previous and subsequent conferences in this series do not include any public involvement. The Q and A session found little objection from the public audience to a change in the regulation and control of drugs including the downgrading of cannabis, which at this time was still just a proposal. Concerns that were raised about any change in law including the possibility of increased risk of progression to hard drugs, the potential health detriments including an increased use of tobacco and the

effect on younger people of any change. Although these responses must be taken in the light of the probable audience attending the event, our consultation uncovered similar concerns. *Drugsfutures* found the public in support of a public health approach to drug use and addiction, rather than one based on the criminal justice system. There was also widespread support for clarification of the classification system, which is seen as confused and not based on the relative harms of the individual drugs. There is little support for ending prohibition of currently illicit drugs. Prospective futures stemming from this report were discussed by a group of experts at a UK-Netherlands meeting on Brain Science, Addiction and Drugs but no public input was solicited.

Cognition enhancers

Previous research into public perceptions of cognition enhancers is limited. The little that has been done is generally small-scale, with an academic focus, and provides little insight into public views. Anders Sandberg, an expert who took part in the cognition enhancer workshop in Glasgow, authored one report which we reviewed. His research suggested that societies stance towards cognitive enhancement is softening and he draws an analogy between the rising acceptance of purely cosmetic plastic surgery and use of cognition enhancement. Participants in our public consultation also made the comparison between enhancing intellectual functions and enhancing the body, either through steroid-assisted bodybuilding or cosmetic surgery. The findings from *drugsfutures* suggest that support for widespread availability of cognition enhancers will be limited, until a great deal more research has been done into their side-effects and into the consequences of long-term use for both the individual user and society.

Evaluation

The independent evaluator of this project will produce a separate report on the evaluation.

Stage 2: Implementation

National engagement

Face-to-face activities took place between 31st January and 31st March 2007. The on-line consultation ran between 31st January and 2nd April. Participants ranged in age from 13 (in Belfast) to 96 (in Merthyr Tydfil). A detailed breakdown of the sample is provided in the Appendix to this report.

Launch event

The launch event was held in the Dana Centre in the Science Museum and organised jointly with EDAB, the BA and other consortium members. One hundred and thirteen people attended the launch and participants fell into four main groups:

- people who would not normally visit the Science Museum or follow science-related issues in the media. These participants were recruited by a professional recruitment agency.
- people with particular interest or experience in these issues such as members of the Meeting of Minds panel; representatives from relevant local groups such as ADDISS – a

campaign and support group for people with ADHD; and young people who took part in the *Drugs Futures 2025?* project.

- general public reserving a place through the Dana Centre's on-line booking system
- relevant professionals comprising members of the Working Group, AMS, policymakers, media and other key stakeholders.

A brief overview of the findings from the launch event and details of those attending can be found in the next chapter.

Face-to-face events

Three hundred people took part in face-to-face events. These included:

- a reconvened deliberative workshop, taking place over 3.5 days in total, with a 1.5 day introductory session at the start of the project and a 2-day session at the end of the project;
- five regional one-day workshops, each of which was organised around a specific theme;
- smaller 'outreach' groups with specific groups

The table on the following page provides an overview of these events, including the themes addressed, numbers of participants and the experts who attended. In addition to the outreach events held in workshop locations, the BA ran three outreach groups, as follows:

Newham – 13th February	Drugs and Mental Health	1 group (African-Caribbean Carer's Forum)
Norwich – 21st February	Drugs and the Law	1 group (St Edmund's Society)
Norwich – 22nd February	Drugs and Society	1 group (Norwich Community Exchange)

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Location/ Date	***Theme***	***Outreach groups***	***Experts***
Birmingham 2nd/3rd Feb & 30th/31st March	Brainbox – all 5 themes	N/A	*Stage 1:* Professor Philip Cowen FMedSci, University of Oxford *Stage 2:* Dr Danielle Turner, University of Cambridge Dr Rebecca Roache, University of Oxford Daren Garratt, Director, UKHRA Keri Tozer and Sue Garnett, Relay Project, Liverpool Robin Felton, Alzheimer's Society Rebecca Swift, Birmingham and Solihull Mental Health Trust
Liverpool – 17th Feb	Drugs and the Law	2 parent groups 1 ex-user group	Professor Roger Brownsword, Kings College London Professor Jonathan Wolff, University College London Niamh Eastwood (Release) DI William Stupples, Matrix Unit (Drugs), Merseyside Police
Exeter – 24th Feb	Drugs and Society	1 student group 1 teacher group 1 user/ex-user group	Professor Les Iverson FRS, University of Oxford Dr Matthew Hickman, University of Bristol Tim Payne, Exeter College
Glasgow – 3rd March	Drugs for a Smarter Brain	2 groups- parents of children with ADHD 1 student group	Dr Danielle Turner, University of Cambridge Dr Anders Sandberg, University of Oxford Dr Brian Canavan, University of Glasgow
Belfast – 10th March	Drugs and Young People	2 young people groups 1 parents group	Dr Patrick McCrystal, Queens University Belfast Sheila McEntee, SE Belfast NHS Trust
Merthyr Tydfil – 24th March	Drugs and Mental Health	1 mental health service user 1 mental health + carers group 1 older people group	Professor Jacqueline Barnes, Birkbeck, University of London Sharon Davies, Hafal Christine Bounds, Gurnos House
London – 19th March	3 drug types (drugs for mental health, recreational drugs, cognition enhancers)	1 user/ex-user group	

Brainbox was a model designed specifically for this project. It used a deliberative approach to involve a group of participants in an extended event, during which they were able to explore all the issues in some depth. Brainbox comprised an introductory 1.5-day (one evening followed by a full-day) event, held at the start of the programme, immediately after the launch. It introduced participants to the issues and allowed us an opportunity to gauge their initial attitudes, hopes and concerns. The follow-up 2-day event was held at the end of the programme. This event provided expert input and built on the results emerging from the five workshops and outreach events. Participants were sent a summary of the initial Brainbox discussions, to ensure they agreed with the analysis and were also sent an overview of the workshop findings before they reconvened, allowing them to measure their own views against those of the wider public and take those views into account when developing their priorities. A young carer who attended the workshop but was not there as an 'official' participant, kept a diary of her thoughts. Pages from this are used through this report.

Outreach events were held with participants from specific groups, including drug users and ex-users, people with mental health problems, young people, parents of children with ADHD, carers and older people. Some of the participants in outreach events attended workshops in their area too. These smaller discussion groups allowed us to gain the input of people whose views might not normally be heard in this kind of project. Their contribution to the success of the work was invaluable.

Workshops were focused on specific themes. Each of the topics addressed within a theme was relevant to at least one other theme, providing comparison across themes and enriching the perspectives brought to each. The same materials that were use in Brainbox were also used in the workshops. Experts provided some additional insight into the issues. An electronic voting system was also used in the workshops: more information on this is provided below.

All materials, including agenda, scenarios, briefing notes and additional information are included in the Appendix.

PP vote

An electronic voting session was held in the morning and afternoon sessions at each of the five workshops. This was done for three main reasons. It gave participants an opportunity to consider some of the issues prior to discussion, which can be particularly helpful for people who have not considered them previously. It also allowed individual views to be expressed without their being subject to group influence. Third, the two-part voting allowed us to see if participant's views had shifted between the morning and afternoon sessions. The data has no statistical value but we have included it in the report to provide an indication of how strongly held participants held some views.

On-line consultation

The on-line element of the project comprised a blog and a structured consultation.

A blog was set up to allow people to join in the debate in a less formal way than by participation in the full on-line consultation. The administrator started a total of 19 discussions which were viewed 1641 times, on topics ranging from the scientific (gene therapy for addiction) to the social (the link between alcohol taxation and drunkenness). Some of the discussion was excellent, especially when a patient and a doctor both joined in debate on depression drugs. But despite the large number of views, no item brought in more than eight extra comments. It was decided in February to stop posting new material to the blog, in a bid to ensure that visitors to the site contributed instead to the main on-line consultation. The blog can be viewed at http://www.drugsfutures.org.uk/blog2/blogs/default.aspx

Invitees were asked to register on-line in order to participate. They were required to provide their name and email address and asked to provide their postcode, organisation name, age group, ethnicity and disability status for monitoring purposes.

The on-line consultation was structured by the five themes used in the face-to-face work. Participants were able to respond to any theme or all and could answer all questions or only those of most interest to them.

Each section began with the future scenario used for that theme in the face-to-face work and a link to the relevant briefing notes, which were in downloadable .pdf format. Beneath the future scenario were a series of 4-6 questions relating to the section, with space for participants to type their answers. The answers were limited to 1000 character or approximately 200 words.

Three hundred and fourteen people registered on the website. One hundred and twenty five people participated in the on-line consultation by answering one or more questions. A total of 1659 responses to questions were submitted.

	Registered	**Participated**
Age		
16-24	36	16
25-39	115	35
40-54	75	37
55-65	46	23
Over 65	7	4
Not specified	35	10
Ethnicity		
Asian or Asian British	6	2
Black or Black British	3	2
Mixed	3	0
White British	215	87

	Registered	Participated
White Other	45	19
Other	4	3
Not specified	38	12
Registered Disabled		
Yes	15	9
No	270	110
Not Specified	29	6

The full report on the on-line consultation is provided in the Appendix.

Recruitment

Public participants – face-to-face outreach groups

Participants who were recruited on the basis of specific knowledge, experience or family situation – for example, mental health service users, parents of children with ADHD, and drug users – were engaged through local contacts in the areas in which activities were taking place – for example, the Exeter Drugs Project or New Horizons, a support group in Aberdare, Wales, for people with mental health problems. Most contacts were recruited through voluntary or community sector groups. Teachers were recruited through local schools. Students were recruited face-to-face, on campus. A number of participants in the outreach work also attended the workshops.

Public participants – workshops

General public participants in the workshops were recruited by a professional recruitment agency. A sample specification and recruitment questionnaires were provided. These are included in the Appendix.

Incentives

Individual incentives were not given to participants in the outreach work. The help given by the charitable, voluntary and public sector organisations that publicised the groups, arranged for people to take part and provided venues and catering was acknowledged with a small financial contribution.

Participants in the workshops received an incentive of £50.

Participants in Brainbox received an incentive of £250.

On-line consultation

Initial email invitations were sent to 162 contacts identified by the project team and AMS, including key organisations dealing with drugs, addiction and mental health. These were supplemented by email invitations to 809 addresses from the ‘Public Service Exchange’ database that includes people from Local Government, NHS, Housing, Higher Education, Regional Government, Central Government, and Criminal Justice. The consultation was

also highlighted on the blog, through postings on discussion lists, and at the launch event at the Science Museum's Dana Centre, with associated media coverage.

Letters were sent out to members of the public in Exeter and Belfast, in the week before the workshops in those cities, inviting them to participate in the on-line consultation. The on-line work was not intended specifically as a way of gaining responses from organisations to the topics addressed in the face-to-face public engagement events. However, the nature of on-line work means inevitably that those who have some prior interest in the topic are more likely to take the time to respond to the questions.

Stage 3: Reporting

This report provides a detailed account of participants' views on the content of the project. It does not cover their views of the process. A separate evaluation report will be published in the summer, drawing on findings from the evaluation questionnaires completed by participants attending events, on the evaluator's own views, following attendance at 1 workshop and Brainbox 2. The evaluation report will also draw on reflective interviews with public participants and other stakeholders involved with the project, carried out after the work was complete.

This report will feed into the AMS Working Group's report to the Department of Health

Terminology

Where the word 'people' has been used in this report, it should be read as meaning those people who took part in this project. It is not intended as a claim that the wider population would share the views of our participants.

We have used the term 'recreational' to apply to illicit drugs currently falling under the UK ABC Classification system, and licit drugs such as alcohol and nicotine. It could be argued that the term 'recreational' is not applicable to some of these drugs – or, at least, to the reasons for their use. This was the term used in the Foresight Drugs Futures 2025 project that preceded this work and we have retained the term in the interests of consistency.

We have also used terms such as 'participate', 'engage' and 'involve' interchangeably. This should not be read as meaning that the debate around the respective use of these terms is considered over.

The film

Elliot Manches, an independent video ethnographer, has produced a film to accompany this report. The film is based on footage shot at the launch event and at Brainbox 1 and 2. It includes individual participant's views on the some of the issues raised and feelings about taking part in the project as well as coverage of some of the discussions and expert presentations. A re-edited version of the film will be produced towards the end of the summer, to include reflections on the findings contained in this report from others involved with the project, including some of the Academy of Medical Sciences Working Group.

Summary of media coverage

National

Broadcast
1 February 2007
BBC Radio 4 Today Programme: Interview with Prof Trevor Robbins FRS FMedSci

16 April 2007
BBC Radio 4 – today programme

16 April 2007
BBC Radio 4 – The Defeat of Sleep

Print
Financial Times, April 17 2007
'Intelligence' drugs are put to the test
By Salamander Davoudi

Daily Mail, 18th April 2007
Fears over drugs that can boost your brain
by Jenny Hope

Daily telegraph 18 April 2007
Intelligence drugs could be 'common as coffee'
By Nicole Martin

On-line Media
BBC Online 16 April 2007
Drugs may boost your brain power
By Pallab Ghosh

Contractor UK – 19 April 2007
UK to sample ‘smart drugs’

Local

Broadcast
9 February 2007
BBC Radio West Midlands – interview with Robert Frost (AMS Brain Science, Addiction and Drugs Project Manager)

16 February 2007
Wirral Buzz – interview with Prof Gabriel Horn FRS
BBC Radio Mersey – Interview with Prof Jonathan Wolff
Radio City – interview with local participant
Century Radio – Interview with Prof Roger Brownsword (AMS WG member) and local participant

23 February 2007
Westcountry Television – interview with workshop participant

24 February 2007
ITV South West – interview with participant and Dr Matthew Hickman

3 March 2007
BBC Radio Scotland – interview with Dr Danielle Turner

Print

Liverpool Echo, Feb 17 2007
City hosts drug laws debate

Big Issue North, Feb 2007

Exeter Express and Echo, 24 February 2007
City hosting drugs debate

International
Hindustan Times, 28 April 2008
Jury is out on wakefulness drug

Gulf News 21 April 2007
Think over this – you could use a memory pill

Wired News 16 April 2007
Smarts in a Bottle: UK Government Evaluates Cognition Enhancers

News-medical.net, 19 April 2007
Modafinil which improves intelligence under scrutiny by Health Department

ABC News Australia – the World Today, 17 April 2007
Smart drugs under examination

3. The launch event

We have included details of the launch event in a separate chapter rather than in the main body of the report. This is because the discussions were brief and, in this short time, the issues could be addressed only in a cursory fashion. The focus was on informal dialogue. By using innovative formats such as performance, as well as more familiar discussion groups, participants had an opportunity to engage with the issues in different ways.

The launch was chaired by Dr Geoff Watts FMedSci and hosted by Sir Gabriel Horn FRS. It included a series of themed round table discussions, with general public and 'expert' participants from policy and science backgrounds. A performance highlighting some of the issues around drug was given and participants were encouraged to move the performance along by suggesting how each actor might respond to the arguments proposed by their fellow actors. Food and drink were available and participants seemed enthusiastic and engaged by the topic.

Many of the views expressed in the discussions were similar to those voiced by participants in the workshops and Brainbox. In discussing mental health, the question of how to define a condition as a 'mental health problem' was debated. One participant reacted angrily to the depiction of a panic attack as a mental illness. Another pointed to the social factors – in this case, bad housing – that might be implicated in mental health problems. A third spoke of prescribing drugs for mental health problems as 'the easy option'. Concerns were expressed too over the role of pharmaceutical companies and the marketing of drugs as an 'easy' solution to problems whose causes were deep-seated. These issues and others raised were discussed in more detail in the workshops that formed the main body of the project.

In the discussion on Drugs and the Law, participants discussed both the harms that arise from our current regulatory approach, including drugs being cut with a range of dangerous substances, and, on the other hand, the importance of the law in sending out messages from society as a whole, to young people in particular, about the use of some drugs. The relative harms and different regulatory framework for alcohol and cannabis were highlighted as an example of the rather muddled current situation. The importance of effective education and information about drugs of all sorts, including illicit and licit recreational drugs and prescribed drugs, was emphasised.

Some participants saw recreational drugs as more socially acceptable and 'cool' than ever and felt that the numbers of young people using them were growing. Some participants pointed to the presence of alternatives – such as getting to university – as an important factor in helping young people to avoid the use or continued use of recreational drugs. The general pressures of life, expressed by use of the term '24/7 society,' were also pointed to as a reason for growing use of drugs, both recreational and prescribed, as people seek to find an escape from competition, and overworked parents lack time to spend with their children.

The following provides an overview of participants attending the launch. Details can be found in the Appendix.

General public	*Scientists and Policymakers*
Public participants arrived at the event through a variety of channels: Booking through Dana Centre website On-street recruitment Invitations to local groups and contacts, including teachers, mental health support groups	Crispin Acton, Programme Manager, Substance Misuse, DH Nick Lawrence, Head of Drug & Alcohol Policy, DH Sue Bolton + colleague, Office of Science and Innovation Stephen Moore, , Head – Crime & Drug Legislation & Enforcement Unit, Home Office Steven Tippell, Head of the Drug Strategy Unit , Home Office Jeremy Clayton, Group Director, Transdepartmental Science and Technology , OSI Gary Kass, Head of Public Engagement , Science and Innovation Group, Office of Science and Innovation, Alison Crowther, Dialogue Director, Sciencewise Sir Gabriel Horn, Chair, AMS Working Group, Brain Science, Addiction and Drugs project Prof Trevor Robbins, AMS Working Group, BSAD project Prof Les Iverson, AMS Working Group, BSAD project Prof Barbara Sahakian, University of Cambridge Dr Danielle Turner, University of Cambridge Dr Kim Wolff, National Addictions Centre, Institute of Psychiatry Dr David Dexter, Imperial College Dr Susan Aldridge, author of ‘Use Your Brain to Beat Addiction’ Dr John Marsden, National Addictions Centre, Institute of Psychiatry Harry Shapiro, Drugscope Liz Brice, campaigner for medical use of cannabis

4. Common themes

The views outlined in this report may seem to some readers to present a very negative view of drugs and our use of them in the UK. To some extent, this is the case. However, the disadvantages of drug use which we identified and the view that we use drugs too much and too easily sit within a wider recognition that developments in drugs have brought many benefits. Asked to identify these benefits, participants responded with the following list. It goes beyond the classes of drug on which this project focused but helps to situate some of the concerns raised later in this report.

What benefits do we gain from drugs?

• Pain relief • To stay alive • Combat organ rejection • Improve performance of athletes • Improve quality of life for people in pain or with problems • Have a buzz	• Help you have children • Help you relax • Anaesthetise you • Stop you having unwanted children • Prevent disease • Treat disease • Prevent travel sickness	• Slimming pills-if they work, you feel better about yourself • Treat depression • Increase happiness • Build muscles following accidents • Treat conditions such as epilepsy

Participants listed too some of the things that makes them trust a particular drug:

What makes you trust a drug?

• Reputation – been round a long time, tested • Had something before and it's worked • Evidence of family members' experience • Doctor or pharmacist's advice – usually tell you if there are side-effects • More likely to trust consultant than a nurse • Available over the counter- assumption that it's ok	• Company names (brand) • Who's giving you the message? • Acceptable side effects – drowsiness, nausea, headaches • Weigh up seriousness of problem against side-effects • Information from the internet – depends on who's writing information – look for personal stories – as much information as possible	• Support group information • Natural, rather than chemically-based • Look for natural alternatives to prescribed medicines • If it's more expensive more likely to trust it • Some circumstances make you more wary – eg, breast feeding, pregnant

They were, however, concerned about the amount of conflicting information on drugs given by trusted sources. One participant said that the advice given by a pharmacist could be different from that given by a doctor. This makes informed decision-making difficult.

Using drugs

A recurrent theme in this project was that, as a society, we choose the 'quick fix' in preference to seeking out longer-lasting solutions to our problems. Participants spoke of drugs being used as a 'sticking-plaster', of the easy availability of drugs – prescribed drugs, licit and illicit recreational drugs – and of their concerns about the implications of this for the future. But despite this, there was support for the individual's right to make their own decisions about whether or not to use drugs, including illicit drugs. The value of drugs in treating the most serious mental health problems went unquestioned, though issues were raised about the way in which these drugs were used and about their side effects.

Freedom of choice and hard choices

What generated most debate were the implications of choice, for individuals, their families and wider society. What would the consequence be of widening or narrowing the choice of drugs that individuals can legally consume, of changing the way drugs are distributed, of improving their effectiveness, or of new information being introduced into the framework within which choices about drugs are made?

For example, if you knew you were genetically predisposed to addiction, what difference, if any, might that knowledge make to your decision to drink alcohol? If cognition enhancers were available, would you give them a try or refuse on the grounds that they would give you an unfair advantage over non-users? If your son had schizophrenia and was considered a danger to himself or others, but was refusing medication, would you argue that it was not likely to be effective if forced upon him, or would you argue that his future would be worse if he did harm someone and that he should be made to take medication?

Is choice rational?

Initially, participants appeared to be assuming that choice was rational. Provide people with accurate information and they will make their choice in accordance with that information. This assumption lies behind the call for 'more education' in response to the question of how young people can be dissuaded from using drugs. However, we know that behaviour is more complicated than that. We know alcohol can be a poison but we drink. We know smoking kills us, but we smoke. We know that heroin is addictive but we use it, despite the potential health, social and legal consequences. We provide education and information of all sorts, on smoking, alcohol, diet and exercise, but the relationship between this and our behaviour is not straightforward. So part of the task facing participants, in relation to recreational drugs at least, was to think about how people behave in relation to drugs, acknowledging that this behaviour is frequently not at all rational, and what the effects might be of changing the scientific, social, legal and economic context of their behaviour.

As they discussed these and other questions, it became clear that participants were not assuming that choice was rational and that sometimes they were not talking about choice at all. They spoke about peer pressure, marketing, different methods of taking drugs into your body, about not wanting to disappoint parents, about a dealer on every corner and shopkeepers willing to sell cigarettes to children under-age, about not knowing you were smoking heroin rather than cannabis and about the failure of prison as a deterrent. Some talked about the pleasures of drugs and others talked about the damage done by drugs to their own lives and the lives of people around them.

This means that while people used the term ‘quick fix,’ they didn’t mean by this that using drugs does actually fix problems or that our choice to take the quick fix is unproblematic. Using drugs, whether these were recreational, for mental health or cognition enhancers, was seen frequently as a way of dealing with symptoms without addressing the underlying problems. Throughout the project, people argued that drug use often starts and continues because the social support needed to address their problems was not available.

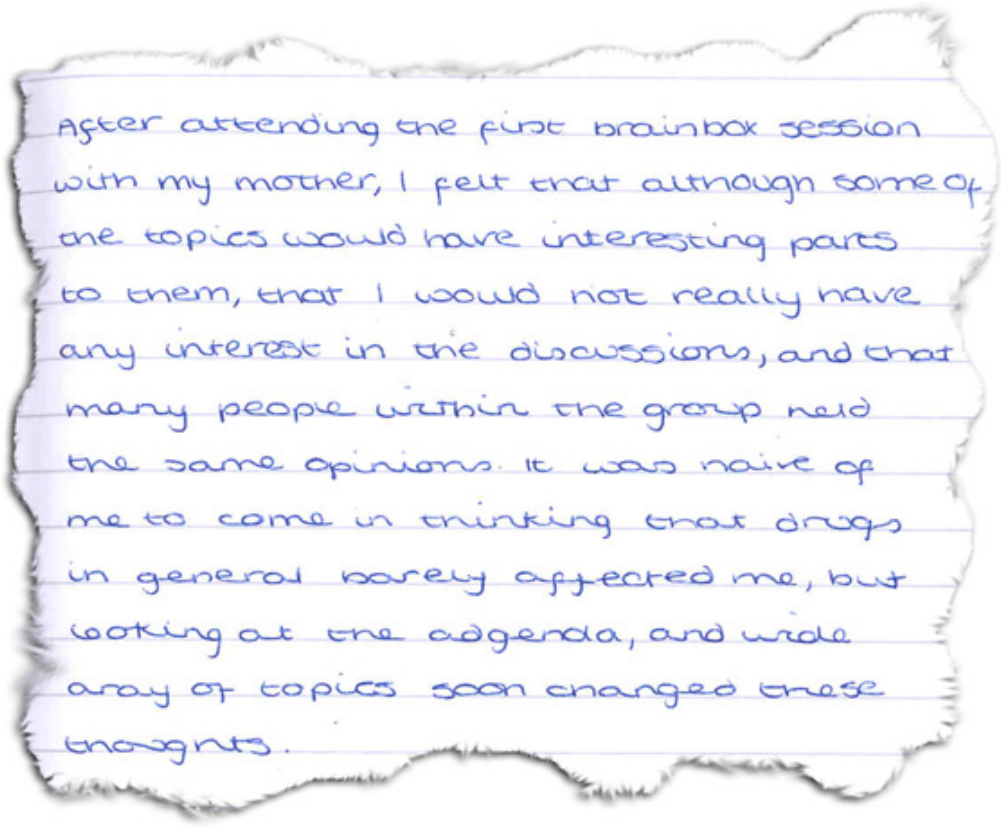
The context of drug use

Again and again throughout the project, participants returned to the need for us to look at the use of drugs within a wider social, economic and environmental context and to adopt other approaches to some of the problems we seek often to fix with drugs. This was most frequently the case in discussion of mental health problems, where alternatives such as cognitive behaviour therapy or just some love and attention were seen as valuable. It was acknowledged that providing additional resources to widen the range and availability of social forms of support would be costly initially. But participants argued that it would, in the long term, save money, since more people would remain able to work and the cost to the NHS of providing mental health services would decrease.

Drugs and young people

Young people’s use of drugs was viewed differently from adult drug use, regardless of the type of drug being discussed. Participants stressed the need to protect the developing brain and to prevent the emergence of patterns of behaviour or attitudes that might lead in later life to addiction or mental health problems. The presentation given in Brainbox 2 by The Relay Project placed particular emphasis on the role of children’s services and the value of supporting the children of people who are addicted to drugs, including alcohol.

EXTRACT FROM DIARY KEPT BY YOUNG CARER ATTENDING BRAINBOX.



After attending the first brainbox session with my mother, I felt that although some of the topics would have interesting parts to them, that I would not really have any interest in the discussions, and that many people within the group held the same opinions. It was naive of me to come in thinking that drugs in general barely affected me, but looking at the adgenda, and wide aray of topics soon changed these thoughts.

5. Drugs for mental health[3]

Introduction

Throughout the face-to-face work, participants recruited as general public recounted experiences of mental health problems, suffered either by themselves or by family and friends. A father told of a son with clinical depression, which had led to several suicide attempts. A woman spoke of a friend with schizophrenia and of the difficulties caused by people's fear of the condition. Another talked about the struggle to find medication for her father that addressed his depression without causing the side effects that seemed at times as bad as the depression itself. A young man recounted his 10-year history of Prozac use. Many others had similar stories to tell and others may well have had experiences about which they were not willing to speak. Some of the people who took part in the outreach work in Merthyr Tydfil and Aberdare were recruited specifically because they had mental health problems. These included bipolar disorder, schizophrenia, depression, paranoia, and generalised anxiety disorder and panic attacks. Some of the people who were using or had used illicit recreational drugs may have done so to help them cope with mental health problems.

This chapter begins with an overview of participants' views of our attitudes towards mental illness. It continues with an account of the factors participants' take into account when deciding to call a particular condition a 'mental health problem' and their views on some of the causes. Next, we look at attitudes towards the use of drugs to treat mental health problems, including the benefits and disadvantages of prescribed drugs and recreational drugs. The final section covers non-drug approaches to treating mental health problems.

Attitudes towards mental health

Stigma and invisibility

Participants did not think that their own openness and honesty about mental health problems was reflected in wider social attitudes. Many described mental illness as 'invisible'. This was meant in two ways. First, and most straightforward, whilst many physical illnesses are clear to see, mental health problems may have no obvious external manifestation. Second, mental health problems are described as 'invisible' because of the stigma they are still felt to carry. Many people quoted a statistic highlighted recently in the media – one in four of us will suffer a mental health problem at some stage in our life. However, despite the prevalence of mental illness, the stigma was felt to leave people reticent to speak of their experiences and to make some sufferers feel ashamed, as if their condition was in some way a sign of weakness. The wider understanding that might arise from a more open discussion of the impact of mental illness on the individual, their family and friends and wider community seems, to many participants, still to be lacking. Whilst a

3 This chapter does not discuss dementia, Alzheimer's Disease or Attention Deficit Hyperactivity Disorder. These are covered in the chapter on cognition enhancers.

few suggested that the stigma had lessened in recent years, it was seen as a continuing problem.

> *'Everyone knows somebody, but no-one talks about it.' (Merthyr Tydfil workshop)*

> *'People walk around saying you are mental, but they don't understand the problems.' (Wales outreach – mental health service users)*

> *'[If I had mental illness] I would not tell people about it, I would feel embarrassed.' (Belfast workshop)*

Some participants felt that the lack of open discussion of mental health problems was compounded by the perception that they are used as an excuse. Rather than being seen as real health problems, conditions such as generalised anxiety disorder or mild to moderate depression may be perceived by some as a pretext for a day off work or a missed deadline. Debate around this issue arose in particular in discussions about whether there were any mental health problems – such as shyness – for which new drugs were needed.[4]

> *'It is an illness, just like cancer.' (Wales outreach – mental health service users)*

> *'People used to say 'you're lazy, why don't you go to work?' You look fit and people judge you based on the way that you look. People often keep these things to themselves, and within their families.' (Merthyr Tydfil workshop)*

> *'There is not a lot of understanding… people often say pull yourself together.' (Glasgow outreach – teachers group)*

For people with severe and ongoing mental health problems, the invisibility of their illness and the difficulty in being open about it meant they had lost friends, work and independence. A woman in the Merthyr Tydfil workshop described how a young man she had befriended had gradually lost friends of his own age, through the onset and worsening of schizophrenia. She felt this had exacerbated his condition, forcing him into isolation. She argued too that this isolation not only placed the young man at greater risk but also held potential risks for the wider population. With fewer people around him to notice changes in his behaviour, she felt it was more difficult to tell if he had stopped taking his medication.

> *'You are forced to be lonely because of the way society works.' (Wales outreach – mental health service users)*

In contrast to the invisibility – but also related to stigma and lack of understanding – was the feeling amongst some participants that the illness became a lens through which all behaviour was refracted. Being grumpy, having an off day or feeling unusually happy tended to be explained in terms of the illness.

The consequences of stigma, invisibility and general lack of understanding were described in a consistent manner by those involved in the outreach work and in workshops. Some

4 This discussion is covered in more detail later in this chapter.

people saw the mental illness itself as less debilitating than the wider social consequences that can accompany the condition, such as isolation and being open to abuse and, at times, violence. They pointed to a lack of understanding amongst service providers – they mentioned the police in particular – as well as the public.

> *'It's easier to approach someone with a leg missing than a nutter.' (Wales outreach– mental health service users)*
>
> *'Having mental health problems, you're living a life of constant abuse.' (Wales outreach – mental health service users)*
>
> *'It can affect your job and your job prospects.' (Merthyr Tydfil workshop)*
>
> *You are scrutinised and discriminated against.' (Merthyr Tydfil workshop)*
>
> *'You get more help if you are a criminal than if you have mental health problems.' (Exeter workshop)*

Media representations of mental illness

Participants felt that media representations of people with some mental health problems – notably schizophrenia and other forms of psychosis – aggravated the general lack of understanding. The phrase 'mad axe-man' was used spontaneously in several different events, by people describing media depictions of people with schizophrenia. They saw these as having a significant impact on social attitudes towards mental illness.

High profile media celebrities who are open about having mental health problems are viewed very positively. Offering an image of mental illness that helps to counter-balance the more negative portrayals, they demonstrate that it is possible for people to succeed despite their problems. Soaps and day-time talk programmes that explore mental health issues are also seen as welcome even if at times they can be upsetting.

> *'It's good when celebrities, like Spike Milligan, come out.' (Wales outreach – mental health service users)*
>
> *'There's some more positive stuff, like Eastenders, Trisha, Oprah. But it can be upsetting to see things on TV and knock you back.' (Wales outreach – mental health service users)*

What is a mental health problem?

Participants were agreed that some conditions could without question be described as 'mental health problems'. Schizophrenia, severe clinical depression, bipolar disorder and dementia including Alzheimer's disease were seen as serious and 'real' conditions for which treatment was important. General anxiety disorder, panic attacks, milder forms of depression, and Attention Deficit Hyperactivity Disorder (ADHD) were acknowledged as 'conditions' but there was debate about whether they were illnesses. Participants in the Newham outreach work also raised epilepsy as a mental health problem.

Two factors seemed to be important for participants in determining what should count as a mental illness. The first was whether there was some underlying physical or chemical cause to which the symptoms could be attributed. The second factor relates to the consequences of the illness for the person affected. Asked if we should develop drugs for conditions that are usually seen as aspects of personality, such as shyness, a majority of participants argued that we should not. If shyness were sufficiently debilitating to prevent one living the life one wanted then, they argued, this would not be shyness but something else – perhaps depression or severe anxiety.

Participants agreed that if symptoms are sufficient to impact on someone's capacity to interact with the world as they choose, the problem can be seen as a mental health problem. If people are genuinely 'just shy', many felt alternative treatments, such as therapy, would be more effective – and appropriate – than drugs. One qualification to this was that there are some mental illnesses – schizophrenia for example – where the person with that illness might be unaware of its seriousness. In this case, rather than the person with the illness identifying themselves as having a problem, it may take those around them to recognise it.

Participants' responses to the question of whether there would be benefits in developing drugs for 'personality-type' conditions link to their concern that drugs are being used increasingly as a 'quick fix' for more deeply entrenched social problems. Many participants saw developing drugs for this kind of condition as part of a general process of eliminating difference from our society. In their presentation on this issue, participants in Merthyr described the idea of developing drugs for 'personality-type' conditions as a '*sad indictment on society*', adding that, *'like fascists- we're trying to make everyone the same with drugs and genetic engineering'*.

> *'If, by shyness, it is meant 'not at ease in the company of others', then I believe there are less invasive ways of dealing with this. Psychologists and counsellors should be able to address the 'problem' quite effectively, but only if it affects the person so badly that they are unable to interact socially and seek help for such a 'problem'. Who will decide which 'features of someone's personality' are desirable or undesirable? The media? Could this boil down to fashionable notions in a period of time? Diverse personalities form the fabric of a colourful human existence and what is seen as undesirable by one person is seen as desirable by another.' (on-line participant)*

A majority of on-line participants shared these views, though some expressed them differently, seeing no problem in developing drugs for things like shyness if there was genuine need, expressed as demand on the part of sufferers or proof that they stemmed from a real physiological problem. Some suggested that they would be a good alternative to self-medication using more damaging drugs. Only a few on-line respondents gave unconditionally positive responses, situating the issue within the context of an individual's right to choose.

> *'Yes [develop drugs for conditions such as shyness]. However they should be viewed as only one possible solution to a problem, rather than a 'one size fits all' remedy.' (on-line participant)*

'Yes, of course. If a person wants to take away their extreme shyness they should be able to do that. Anger, extreme shyness, etc. are all negative personality traits that many people would like to get rid of. Of course though it is all up to them and no one should force a person to take a drug that alters their personality. But should drugs be available to help people with negative personality traits if they want to get rid of? Of course.' (on-line participant)

Addiction

In the pecking order of socially unacceptable conditions, addiction is further down the scale than 'real' mental illness. Participants saw addiction as a special case and there was much debate about whether it was a form of mental illness. Whilst addiction has potentially devastating effects on someone's ability to cope, many people saw it as self-inflicted and the result of bad choices and thus they regarded it as being in a different category from other mental health problems. However, there were participants who argued that, regardless of the initial reasons for using the substance that led to addiction, once addicted, a person should be thought of as ill. This is consistent with the view that drug users should be given health and social support rather than imprisoned, an issue explored in a later chapter.

'We are more sympathetic to people that have a recognised illness, people with addictive personalities are considered to have done it to themselves.' (Exeter workshop)

'With physical and mental illnesses there is more awareness. An addict, you tend to think has brought it on themselves. We are more lenient to someone with mental health issues.' (Exeter workshop)

Some participants argued that we do not know what 'normal' means and that the most we can say is that people have different mental states, some more adequate to coping with the pressures of life than others.

'We don't even know what 'normal' is.' (Exeter workshop)

'We are all basically mentally ill.' (BB2)

Causes of mental health problems

A majority of participants identified modern life as a primary factor in the increasing incidence of mental illness. This includes the pace of life, pressure to achieve in education and work, changes in family structure and neighbourhood relationships and a general feeling that people have too little time to look after their own wellbeing and that of people close to them.

'Depression is brought by modern living. We were happier, just come out of the war, feeling of euphoria. Today there are a range of pressures on young people to achieve. Family life was also very strong after the war.' (BB1)

'There are underlying issues, why you are depressed…Life is always in the fast lane.' (BB1)

Some participants felt there was an inherited aspect to mental health problems, particularly depression, providing examples from their own families of uncles, grandmothers or sons who had all suffered similar symptoms.

The use of recreational drugs was seen as a potential cause of mental health problems. Participants referred to media coverage of 'skunk', some of which included stories of violent crimes said to be committed under its influence. The relationship between mental health and recreational drug use is covered in detail in a later section and in the chapter on young people, in the context of whether young people with ADHD are more vulnerable than their peers to use of recreational drugs.

Identification and diagnosis

Many participants felt that they did not know enough about mental illness and would not be able to tell if someone close to them was becoming ill. One participant who cared for her son, who had schizophrenia, described his increasingly unusual behaviour and how she had thought he was just '*growing up*', not realising that he was ill until her daughter said he was *'clearly mad*'. Many participants discussing mental health problems pointed out that people with conditions such as schizophrenia were often not aware that they were ill and that their behaviour could be bizarre. Some of the participants in the outreach work in Wales described the course of their own illnesses and how different their own understanding of their actions was from the understanding of those around them.

Participants debated the benefits and disadvantages of early professional diagnosis of mental health problems. They agreed that professional diagnosis was important but some felt that, if done too early, it could lead to labelling or a kind of fatalism. Others argued that early diagnosis would allow preventive steps to be taken and resources to be targeted where need was greatest. People involved in the London outreach work suggested that diagnosis was '*a belief system'* rather than a science: '*you have a problem because we believe you have one.'*

The question of diagnosis arose too within the context of discussion about genetic tests to determine whether a young person had a higher than average likelihood of developing a mental illness. This is discussed in Chapter 7, in the context of identifying vulnerability to mental illness or addiction.

Drugs and mental health

We noted earlier that a great majority of participants felt that drugs were used too early and too quickly in treating mental health problems. Many felt too that an increasing number and range of 'mental states' are being seen as problems and that consequently we are using a greater number of drugs for a greater number of 'conditions'. Drugs were also seen by many as a means of controlling those whose behaviour we do not understand or find difficult to deal with or which means they are not viewed as productive members of society,

where ‘productive’ means economically and socially independent. Some questioned whether drugs were used because they were was the cheapest option, but not necessarily the best, whilst others suggested that drugs marketing by pharmaceutical companies played a large part in their increased use.

> *‘Are we going for the best option or just the cheapest option?’ (BB2)*
>
> *‘Often they are treating the symptoms and not the cause. It is a short term fix and you will then be committed to a long term commitment.’ (BB2)*
>
> *‘They shove these pills down your gob.’ (Merthyr Tydfil workshop)*
>
> *‘There is no quick fix for mental health problems, despite the claims of drug companies and the vote catching statements of politicians. It's a long term job, unfortunately.’ (on-line participant)*

In the face-to-face activities, debate about the underlying factors that might help to explain this perceived increase fell into two broad camps. One focused on the individual. Those in this camp suggested that individuals expect their GP to provide them with a drug for everything that ails them and are dissatisfied if they do not walk away with a prescription. A few thought that individuals used ‘stress’ or ‘panic attacks’ as an excuse for shirking and that a prescription for drugs was a way of validating this behaviour.

> *‘You can just go to your doctor and say you’re ‘feeling down’ and the doctor will give you anti-depressants.’ (Merthyr Tydfil workshop)*
>
> *‘People are too quick to say they have depression – there is a difference between someone who is down for a week and someone that is clinically depressed. People should be diagnosed as depressed as a last resort.’ (Merthyr Tydfil workshop)*

Some concentrated on the doctor, rather than the patient. Doctors were seen as being too willing to prescribe drugs in response to non-specific claims of having ‘the blues’, rather than addressing the contributory factors. But the view that drugs for mental health problems were easily available through the health service was very much in the minority amongst those most familiar with mental illness. The people in the service users groups in Wales and others who had personal experience of suffering mental illness said that the situation was instead that one had to be in crisis before help became available.

The majority view was that individual behaviour relating to use of drugs for mental health problems should be seen within the wider social context. The pace and pressure of life mean that taking care of oneself – especially of one’s mental health – was increasingly difficult. This has two consequences. One is that more people are presenting with mental health problems. The second is that, for many of these people, a drug that enables them to carry on with regular responsibilities is the only viable option, even though some pointed out that the side effects of mental health drugs make many everyday activities more difficult.

Some who took this view pointed to the pressures on doctors caused by targets and drugs marketing, and the limitations imposed on them by short consultations. Articulate patients

were felt to be able to come straight to the point and explain their problems within their allocated time whilst those who had more difficulty in expressing themselves – for whatever reason – were placed at a disadvantage.

> *'Our first concern should be our health – you can't make money if you're ill.' (BB2 2)*

> *'If you go to a doctor you're just going to be prescribed something when there's actually so many other approaches.' (Merthyr Tydfil workshop)*

Many questioned whether drugs were being prescribed in the interests of the patients themselves or to make life easier for those around them.

> *'Do they want the mental health drugs to enhance people's lives or are they going to be used to control people?' (BB2)*

> *'Medicine helps, but it is just an intermediate step.' (Wales outreach – mental health service users)*

> *'Medication can go a long way but it can stop you leading a normal life – like you can't drive and things.' (Wales outreach – mental health service users)*

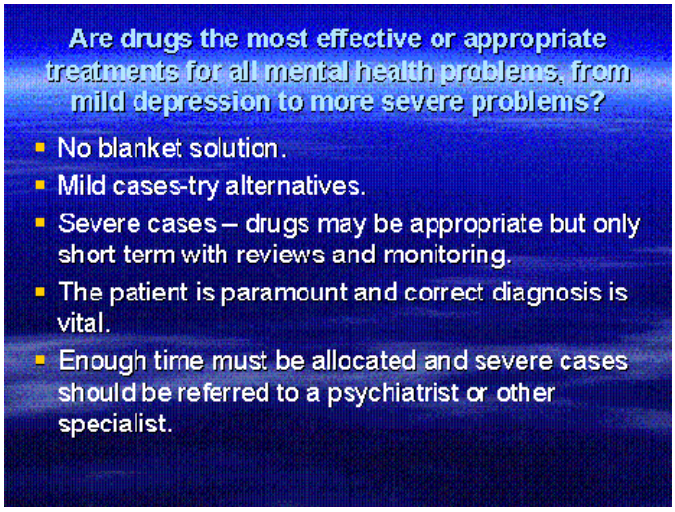
Appropriate use of prescribed drugs

Despite what might seem from the preceding section to be an overwhelmingly negative response to using drugs for mental health problems, there were some illnesses for which their value was clearly acknowledged. Appropriate use was seen as subject to specific conditions. First, the decision about the drug to be used and the dose needs to be made by both the doctor and the patient. Second, drugs should be used only if the particular medication has been proved effective in the treatment of the problem in question and other approaches have been exhausted. Third, on-going support should be available and accessible, to help the person come off medication as early as possible. Some participants felt that what they described as the 'sticking plaster' approach to medication could mean that the problem was seen as 'solved' once the prescription had been filled. Fourth, legible and comprehensible information about the potential side effects and contra-indications needs to be available.

> *'[M]any people who visit the doctor with [depression] are suffering because of issues/emotional trauma through loss of loved one/friend/job etc. Anti depressives such as seroxat are the last thing such people need: maybe only time can heal this type of emotional upset. I have taken lithium sulperide, seroxat and haloperidol myself for many years and, apart from the lithium, I and my partner of 12 years have been able to vary the dosages so I only take them when I know I need them. This was after many rows with my GP who now accepts that I am competent to do this. Far too many prescriptions are at set dosages/times with no option for change, and a lot of people are zombies because they are made to feel powerless by GPs who just write repeats. [GPs] have a bad habit of thinking they know more about a person than the person concerned does.' (on-line participant)*

In the slide below, participants from Merthyr Tydfil describe their views on the appropriate use of drugs for mental health problems. A patient-centred approach means that no single solution will be possible: every patient needs to be treated according to his or her needs and wishes. Drugs are seen as necessary for more severe illnesses, but every effort should be taken to use medication for as short a time as possible, with alternatives available for people when they are coming off drugs and for people with less serious conditions. Sufficient time for accurate diagnosis and correct prescribing is also seen as necessary.

SLIDE FROM PRESENTATION BY PARTICIPANTS



'Drugs are only ever part of the answer. We also need action on the societal conditions that foster mental illnesses' (on-line participant)

'[Drugs are appropriate o]nly if the condition is incapacitating or dangerous to the person affected or others. A bit of eccentricity makes the world go around and progress is usually achieved by bloody minded monomaniacs.' (on-line participant)

Forced use of prescribed drugs

Participants found it very difficult to answer the question of whether there were circumstances under which people with mental health problems should be forced to take drugs. Those who said there were no such circumstances raised two points. First, that forcing people to take drugs would be an abuse of personal freedom. Second, that forced treatment was unlikely to be effective, leading to mistrust and resentment of the medical profession.

'They should never be required to take any drug. You can't force someone to take a drug if they don't want to. The best we can do is encourage them to take it but we can't violate their freedom and force them to take the drug. It's that simple.' (on-line participant)

'You can't force people to take medication.' (Merthyr Tydfil workshop)

Other participants weighed the human rights of the patient against those of wider society. They suggested that there might be occasions on which precedence should be given to the rights of others, rather than to those of the patient. A few participants in the on-line work agreed with this, but uneasily, suggesting that the answer would depend on who defines what is and what isn't a 'mental health problem' and raising the potential for the 'medicalisation' of dissent.

'Difficult – I think it might depend on how serious their behavioural problems became if they didn't take it. To force someone to take a drug is infringing their human rights. On the other hand if they are a serious nuisance or danger to society (and perhaps to themselves) if they don't take the drug then other people's human rights may need to come first.' (on-line participant)

'If the condition is severe and they are danger to themselves or others they should be given drugs with or without consent.' (Merthyr Tydfil workshop)

Some participants in the Merthyr Tydfil workshop suggested that people with mental health problems that may in the future become more serious should be encouraged to develop a 'crisis plan'. This would specify how they wished to be treated should their condition worsen to the extent that they were unable to give informed consent to drug treatment seen as necessary by health professionals. They did not discuss what alternatives should be in place for people whose plans specified no drug treatment but who were considered a danger to themselves or wider society.

'If they state in [the crisis plan] that they don't want treatment, this should happen. When they are well they make those decisions for when they are in crisis.' (Merthyr Tydfil workshop)

Benefits of prescribed drugs

People with severe mental health problems recognised how valuable drugs had been in stabilising their condition. Participants who had long-standing mental health problems spoke of improvements in the drugs available, focusing on the reduction in unpleasant side effects. They spoke of being able to recognise the gait of someone using haloperidol and argued that it was often the effect of the drug on appearance and behaviour that led people to describe them as 'crazy', rather than the illness itself. There was clear support for recent improvements in mental drugs and for research into further improvements in the future. They did not dispute the use of drugs where these are effective and taken voluntarily.

'Earlier drugs like haloperidol, made you stiff and look weird. It's better now.' (Wales outreach – mental health service users)

'Medication can go along way but it can stop you leading a normal life – like you can't drive and things. (Wales outreach – mental health service users)'

'In the worst case there is a need for medication.' (Exeter workshop)

People caring for relatives or friends with mental illnesses were also aware that drugs were at times the only option. The improvements in people's conditions resulting from prescribed drugs could be noticeable and changes in behaviour were marked if medication was stopped suddenly.

The conditions for which drug treatment went unquestioned by general public participants tended to be those to which most fear was attached – in particular, schizophrenia and other psychotic conditions. Media reports of people committing violent crimes were often referred to in discussion of the importance of drug treatment being given and continued in cases of schizophrenia. This was one of the only conditions for which it was seen as acceptable for drugs to be given without patient consent.

The overall view was that drugs for mental health have a clear role but that they are often used too easily in the first place and continue to be prescribed for too long. Too little thought is given by consultant psychiatrists to the adverse effects that accompany the benefits, and too little money is put into providing support for people to come off drugs.

> *'The meds will help so much but the rest, you've got to push yourself.' (Wales outreach – mental health service users)*
>
> *'Drugs are good for treatment but so is counselling' (Newham outreach – carers group)*

Disadvantages of prescribed drugs

In some cases, it was difficult for people to disentangle the benefits of a drug from the disadvantages of the physical side effects and the possible consequences of over-long use. A drug might help to alleviate severe depression, for example easing suicidal tendencies, but the drowsiness or muddle-headedness that accompanied this benefit were in some ways,seen as equally debilitating since they prevented the recipient from carrying on a 'normal' life. One man spoke of his son being unable to bring the necessary attention to his job as an engineer because of the drugs he was taking for depression.

Participants identified a number of disadvantages to drugs prescribed for mental illness. Those who had used these drugs, and people caring for others with mental health problems, tended to focus on the side effects, which they described as extreme and not sufficiently acknowledged by consultant psychiatrists. Their concern lay with both the immediate side effects and the possible impact of drugs on their future health. When participants focused on priorities for future research, minimisation of side effects was high on the list (this issue is discussed in more detail in a later chapter).

> *'Amisulpride was awful. It affected your kidneys. It was a nightmare.'*
>
> *'You have leg pain, stiffness, jerks, sore kidneys, nightmares…'*
>
> *'The throwaway line from a lot of professors is 'the side effects are worth it'. Well, worth it for whom?'*

'Anti-psychotics can cause long-term effects. They may bring on Alzheimer's or affect your liver.'

'It's very rough and ready at present – it's make it up as you go along.'

(Above quotes all from Wales outreach – mental health service users)

'My husband has tried a number of drugs for eight years, it has taken him eight years to find the right combination.' (Merthyr Tydfil workshop)

Many participants discussing mental health drugs felt they were used to 'quieten down' people to render them less troublesome and disturbing to society and the people responsible for them, rather than to treat the person with the illness. The claim was linked to the status of people with mental health problems generally, which is seen as low, to their powerlessness and to society's discomfort with mental illness. Some participants felt that using drugs for this purpose was likely to mean they were used when other treatments would be more beneficial, or that higher doses were prescribed than necessary, or that those prescribed were not the most appropriate for the patient's condition.

All participants saw benefits in a more careful and informed approach to prescribing mental health drugs which placed the needs of the patient at its centre. This included giving more thought to the effect on the patient of changing their medication, either by increasing or reducing the dose or prescribing a different drug. People in the Wales outreach work described worrying about the impact on their condition of their doctor changing their medication. This would mean having to learn how to cope with a new range of side effects or spend time increasing or decreasing the dose until the correct measure was found. Much of this discussion was also about the powerlessness of the patient in relation to their consultant in decisions about medication.

'They dope you up to keep you quiet so they can have a quiet life.' (Merthyr Tydfil workshop)

'A lot of people are given medication when they don't need it – they chuck it at you.' (Wales outreach – mental health service users)

'It appears more humane – a psychological straitjacket is less easy to identify than a physical straitjacket.' (London outreach – user group)

'Drugs just keep you quiet so you are not a problem – drugs just deal with the symptoms.' (Wales outreach – mental health service users)

'If you see the psychiatrist once every six months you end up terrified because you don't know if they will change your medication.' (Wales outreach – mental health service users)

'Where is the human side to a tablet?' (Exeter workshop)

As noted earlier, some participants argued that what they saw as some of the causes of the increase in mental health problems – the pressures and stresses of life – could also be seen as the reason why people took prescribed mental health drugs rather than using other

approaches. Drugs were felt to act quickly and, in many cases, effectively at first. This meant that symptoms were addressed, enabling the person to continue with their life. However, the initial effectiveness could, participants felt, be bought at a cost of addiction, or the underlying causes of the problem going untreated.

> *'Too many people depend on medication like it is a magic wand.' (Wales outreach)*

Availability of prescribed drugs

A majority of participants in on-line and face-to-face work felt that most drugs for mental health problems should be available on prescription only, rather than over the counter at the chemist or health product shops. The exceptions were those that are currently available– for example, St John's Wort – or treatments for mild or moderate depression and anxiety. Participants emphasised the importance of correct diagnosis and accurate prescribing for people with mental health problems and some suggested that wider availability of drugs would lead to more people seeing themselves as 'mentally ill'.

> *'You should be diagnosed by a professional, that can be a GP but it is better if it is a psychiatrist, psychologist or a mental health practitioner. You need to understand the degree of mental health problems, what are the side effects of medication, whether this can cause depression or suicide.' (Merthyr Tydfil workshop)*

> *'Drugs for mild/moderate depression or anxiety should be offered over the counter at pharmacies, as they could then be readily available to anyone at any time who might need a short term help with feeling depressed. However the stronger medication for more serious conditions should still be prescribed by the doctor/consultant.' (on-line participant)*

Mental health and illicit drugs

The relationship between mental illness and illicit drug use was debated by participants in both the recreational drug and mental health drug workshops and outreach groups, and by people discussing drugs and young people. Participants in the on-line work and the drug user groups also raised this issue. Some – although not many – felt that self-medication with illicit drugs could at times be a positive alternative to prescribed drugs, though this view was not widely expressed. A majority of participants in all the work focused on the negative aspects.

> *'Self-medication to a large extent is to do with powerlessness and medicating the pain away.' (London outreach – users group)*

People using illicit drugs and people with mental health problems were more likely to see the relationship as circular. Having untreated mental health conditions could lead to self-medication with illicit drugs that may in turn exacerbate the initial condition, leading to escalating drug use. Many of the participants recruited as general public focused on the consequences for mental health of using illicit drugs, pointing to media reports of psychosis related to use of 'skunk,' and people committing violent crimes under its influence.

Because participants linked addiction primarily with illicit, rather than licit, recreational drugs, the argument is complicated by the legal status of the drugs themselves. People in face-to-face work who saw addiction as a choice tended to focus on its link with crime. The relationship between the use of alcohol and mental health problems was not raised.

> *'People do, to some extent, have control over whether they are consumed by their addictions. The same cannot be said of mental health problems.' (on-line participant)*
>
> *'Addiction is not a mental health problem.' (Merthyr Tydfil workshop)*
>
> *'We don't put mental health and drugs issues under the same heading as there are issues surrounding addiction such as crime.' (Exeter workshop)*

Others, pointing to the possibility of a genetic element in addiction, argued that if mental health problems lay behind use of illicit and addictive drugs, then addiction should rightly be seen as a mental illness.

> *'Street drugs are causing mental health problems – you use street drugs to help you feel better – it's like a vicious circle.' (Wales outreach – mental health service users)*

In Belfast, participants focused on services for people with mental health conditions who are also using illegal drugs. Like other mental health services, these were seen as inadequate. The expert from South East Belfast NHS Trust described how women with whom she worked found it difficult to get access either to mental health services or to drugs services. Mental health services were refused on the grounds that the applicant was an addict, while drugs services were refused on the grounds that the applicant was mentally ill. This problem was seen as a consequence of both lack of resources and the way in which resources were distributed across the different services. Participants felt this needed to be resolved.

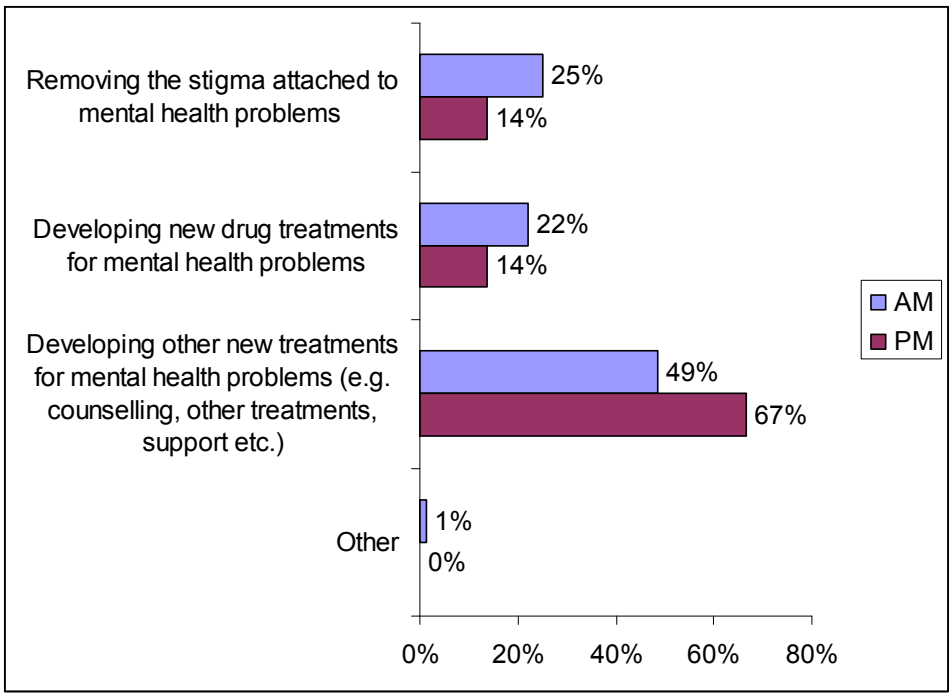
Non-drug approaches to mental health problems

A majority of people in both the face-to-face and on-line work thought that a wider range of non-drug treatments and support should be available for people with mental health problems. At present, non-drug treatments and services for people with mental health problems are seen as inadequate in type, quality and availability. People in rural areas in particular may find it especially hard to get the support they need. When describing what good mental health services might look like, participants emphasised that environmental factors, including family situation, work, homelessness and other issues need to be addressed as well as the illness itself. Ensuring that services function as advertised is also important. They need to be well staffed by people with experience and knowledge. Having a number to call that rings unanswered may be worse than having no number at all.

> *'Talking therapies are very, very scarce around here.' (Merthyr Tydfil workshop)*
>
> *'There is no real choice offered, there isn't acupuncture, tai chi available on the NHS but drugs are.' (Exeter workshop)*

As the following graph indicates, participants in both the Merthyr Tydfil and the Exeter workshops felt that developing non-drug treatments would bring the most benefits to our approach to mental health problems in the future. This data has no statistical significance but illustrates the majority view of all those who discussed these issues across the locations.

WHICH OF THE FOLLOWING WOULD MOST BENEFIT THE WAY WE APPROACH MENTAL HEALTH IN THE FUTURE? MERTHYR TYDFIL, EXETER (N=72)



Participants described a range of different types of non-drug treatments as beneficial for people with mental health problems. These included:

- therapy, including cognitive behaviour therapy, psychotherapy, group therapy, and hydrotherapy
- neuro-linguistic programming
- treatments to aid relaxation, such as massage, herbal remedies, reflexology, acupuncture and meditation
- help lines staffed by knowledgeable and trained people, to whom you could talk at times of crisis
- 'energy' or 'power' therapies treatments such as 'tapping', seen as valuable because you can 'carry them with you'[5]
- support for a healthy lifestyle, including improved diet and exercise, achieving a better work-life balance and reducing stress
- projects to help people recover social and work skills

5 'Tapping' is a process by which anxiety, for example, is said to be alleviated by the sufferer tapping specific points on their body gently and repeatedly. One participant with generalised anxiety disorder was already aware of this treatment.

Activities to help people divert their attention out into the world, in particular if they are coming off medication, were seen as vital.

> *'You need someone to talk to, something to take your mind off yourself.' (Wales outreach – mental health service users)*
>
> *'It's like a child growing up, learning the steps again.' (Wales outreach – mental health service users)*
>
> *'My partner [who has schizophrenia] has a number to ring, but when you ring nothing happens.' (Merthyr Tydfil workshop)*
>
> *'Provide safe and pleasant places staffed by kindly people with commonsense who would be available just to chat to people when we sufferers need a retreat from the world and a relief from our distress. … A little bit of TLC would go a long way to healing some of our scars.' (on-line participant)*

Support, love and understanding from friends and family were seen as very important. A participant in the Wales outreach work noted that the psychiatrist is paid to listen to you and that there was often more value in knowing that someone was listening to you because they wanted to. Some of the on-line participants suggested re-instating family values (without these being specified). Reducing the stigma and widening support from society in general were also seen as important as noted at the start of this chapter.

The needs of carers were not discussed in detail. Briefly, they were seen as neglected and very important, particularly for people who had been institutionalised and then returned to the wider world. More and better information about an illness and its symptoms as well as support in coping, were seen as necessary.

> *'Carers need someone to guide you…up until now it has been trial and error.' (Merthyr Tydfil workshop)*

Conclusion

Participants are clear that drugs have a very valuable role to play in treating mental illness. They would welcome more nuanced prescribing and the services that would allow doctors to explore other forms of treatment, for less serious conditions in particular and to help people who have used drugs to treat mental illness to stop using them. The stigma that still surrounds mental health problems and the resulting difficulty in being open about suffering from depression or schizophrenia are deplored. Addressing this is seen as fundamental to our future approaches to mental illness and to the appropriate use of treatments and development of support, both drug and non-drug based.

6. 'Recreational' drugs[6]

Introduction

In the discussions of recreational drugs, participants tended to focus on illicit and addictive substances, such as heroin and cocaine. These are the 'headline' recreational drugs, associated with crime, disruption to families, financial ruin, ill health and overdose. Cocaine use was felt to be subject to double standards. Participants accused the media of depicting monied and celebrity users as glamorous and decadent, occupants of a glittering world far removed from the reality of cocaine addiction. Celebrities and the wealthy were also not thought to be subject to the same legal regime that applies to 'ordinary' users – especially those in financial straits. Following a brief fall from grace, the more glamorous cocaine users are soon able to reclaim their position and continue with their lives.

Most of the people who took part in this project as 'users' or 'ex-users' had experience of addiction and of the devastating impact it can have. All suggested that the impact was worsened by the way in which we approach the use of illicit recreational drugs. Some 'users', however, were using drugs regularly without the dire consequences attached to headline recreational substances. They pointed out that millions of people in this country do the same. Participants in the Norwich outreach workshops, made a strong distinction between non-addictive and addictive drugs, focusing particularly on the difference between heroin and other recreational drugs.

It is difficult to find people who are willing to take part in projects such as this and be open about the use of stimulants such as LSD and MDMA. Fear that the consequences might include entanglement with the criminal justice system, leading potentially to job loss or other undesirable outcomes, means that the views of 'happy' drug users are less prevalent in this work than perhaps reflects their numbers in society as a whole. The chapter focuses more on the harms identified by general public and by users and ex-users of addictive drugs and says less about the benefits that might follow from the use of some recreational drugs.

This chapter starts by looking at attitudes to recreational drugs, what they are and who uses them. We look next at participants' views of who uses recreational drugs and the consequences of use, including perceived harms and whether a distinction is made between drug use and problem drug use. The final section looks briefly at participants' views of drug services. Control and regulation of recreational drugs are covered in a later chapter.

6 Unless otherwise stated, 'recreational drugs' includes alcohol and nicotine as well as illicit so-called recreational drugs. We acknowledge that this may not be an appropriate term to describe all types of drug use explored in this chapter, but use it for the sake of distinguishing it from prescribed mental health drugs and cognition enhancers.

Attitudes towards recreational drug use

The attitude many participants took towards recreational drug use could be summed up in the phrase 'I don't mind as long as it doesn't harm me.' However, whilst accurate, the phrase sounds callous and does not capture their attitudes towards the drug user or their views of how society and the law should respond to problem drug use. This was the topic of passionate and sometimes heated debate.

> *'I would leave each to their own.' (Wales outreach – older people)*
>
> *'Should be freedom of choice as long as they are not harming others.' (BB2)*
>
> *'If people want to use recreational drugs, let them. The problem is theirs.' (BB2)7*

Much of the discussion in the workshops focused on heroin and addiction, and on cannabis and young people. Participants were reminded throughout the debate that alcohol and nicotine were recreational drugs as well as those more commonly thought of in this category. However, their legal status and common use amongst participants meant that the distinction between them and other recreational drugs was frequently emphasised. Participants in the outreach groups who were current or ex-users of illicit recreational drugs took a wider view. The distinction between licit and illicit drugs played less of a role in their attitudes towards the drugs themselves. The people in the drug user groups used the distinction primarily as a way of illustrating the harms felt to arise from prohibition.

What are 'recreational' drugs?

Asked what recreational drugs are, participants identified a range of substances. This section outlines participants' views of the drugs identified. Following this, we provide a list of drugs classed by participants as 'recreational' but not discussed.

Alcohol

Because it is legal, most participantgs view alcohol differently from other recreational drugs. Only the people in the user and ex-user groups were consistent in ignoring this distinction in their discussion of the harms attaching to the use of recreational drugs. They did refer to alcohol's legal status to illustrate the inconsistency in the drug classification system. They regarded alcohol use as being at least as harmful as heroin use.

> *'Alcohol and legal drugs can be more dangerous – attitudes to those will change.' (Norwich outreach – discussion group)*
>
> *'Alcohol is easier than taking a drug.' (Belfast workshop)*

Alcohol was identified as one of the most harmful recreational drugs for young people, more harmful than cannabis, nicotine and heroin. Participants were well aware of alcohol addiction and the social harms attaching to its use, primarily violence. They were very concerned about the rising use of alcohol by young people. However, the legality of alcohol

7 This quote and the one above it are taken from Information Logs completed by each participant in BB2.

use, its easy availability and the acceptability of its consumption by adults in a wide range of settings leads participants to place its moderate use in a different category from moderate use of drugs such as cannabis or ecstasy. One of the effects of alcohol use identified by participants in Belfast was that of making use of other illicit drugs more likely.

> *'People might try other things while they are drunk.' (Belfast workshop)*

Teachers in the outreach work in Exeter pointed to alcohol use by young children as the 'next big issue'. They argued that alcohol was more socially acceptable and easily available than illicit recreational drugs. It is also easily disguisable: they mentioned checking students' water bottles to see whether they contained water or vodka. In Belfast, workshop participants described alcohol use as 'endemic', pointing again to its social acceptability and easy availability as key factors in what they saw as a growing problem of children drinking. Lax age checks in clubs and bars were, they suggested, allowing under-age drinking to increase, as was the way in which alcohol was marketed. Young people in the Belfast outreach work also raised this issue.

> *'Alcohol is legally pushed on young people.' (Belfast workshop)*
>
> *'It is the alcopops – they are just targeted at the young people.' (Belfast outreach – young people)*
>
> *'They make so much money for the companies so nothing will ever happen but they are the worst thing to happen to young people drinking ever.' (Belfast outreach – young people)*

Young people in the outreach work in Belfast acknowledged the increasing use of alcohol by their peers, highlighting what they saw as the ineffectiveness of a prohibitive approach. Alcohol was seen as the drug primarily responsible for aggression, in both young people and adults.

> *'Kids round here are drinking younger and younger.' (Belfast outreach – young women)*
>
> *'You're told not to drink – you drink. It's just what you do when you're a kid.' (Belfast outreach – young people)*
>
> *'Nowhere for young people to go in this area so people drink for entertainment' (Belfast outreach – young women)*

The young people who came to the Belfast workshop pointed out that adults fail to acknowledge fully the harms associated with alcohol, and to see their own moderate use of this drug as no more dangerous than the moderate use of some street drugs. Whilst for the most part, it is teachers who speak of being able to spot the young people in their class who are using drugs, one young person had a different perspective on the impact of drug use in school:

> *'You can tell when the teachers have a hangover – there they are, with their Lucozade.' (Belfast workshop)*

Cannabis

The debate on cannabis was polarised between those who felt it should be legal to buy, under particular conditions, and those who felt that the reported trend towards higher levels of THC – widely publicised in the media over the past year – meant that its reclassification as Class 'C' needed to be rethought.

Cannabis use was seen as ubiquitous amongst young people. Teachers in Exeter said that young people were arriving at school and college in the morning already having smoked a spliff, and that consumption continued at breaks and lunchtime. Some felt they were seeing higher levels of mental health problems amongst their students and attributed this to the use of cannabis in particular, but also to cocaine use, which was also seen as increasing. In Glasgow, teachers felt that the catchment area of their school meant that it was less affected than other schools by drug use amongst its students. They were more concerned about alcohol use.

Many participants felt there was a strong link between cannabis use and mental illness, though the nature of the link was disputed. Some felt that cannabis use would trigger mental illness and could propel people towards violent behaviour. Others argued that people who were more prone to anxiety or depression might seek out drugs – including cannabis – to relax them. This debate on the relationship between mental health problems and drug use is dealt with in more detail elsewhere in the chapter on mental health drugs. Participants in the Norwich outreach group raised the question of cannabis as a gateway drug, but did not see any necessary relationship between use of cannabis and harder drugs. This issue was not raised elsewhere.

> *'There's not necessarily a natural progression from cannabis to harder drugs, but some people will take anything.' (Norwich outreach – discussion group)*
>
> *'Everyone round here smokes weed. And they're all brain dead. Don't go to school.' (Belfast outreach, young people)*
>
> *'Marijuana should not be a class C drug, it should be legal.' (Exeter workshop)*

Cocaine

Attitudes towards cocaine amongst a majority of the general public participants were informed by media reports of celebrity use of the drug. They were very critical of what they saw as double standards, with celebrities making the papers, being castigated for a brief period and reappearing a short time later as if nothing had happened. They felt this was in sharp contrast to the treatment the 'ordinary person' was likely to receive. In their discussion of cocaine use, participants in the Norwich outreach work suggested that these double standards applied more generally. Having money and therefore not having to commit crime to fund drug use makes it appear 'less seedy' and this is seen as unfair.

There was little discussion of the specific effects or potential harms of cocaine use. Teachers were very aware of its increased use amongst young people and many of the users and ex-users saw it as extremely harmful.

'Cocaine has a cool image…people think of famous people taking it and role models.' (Liverpool outreach – users/ex-users)

'It allows rich people to buy drugs, which they can afford so it has no links with crime so it becomes less seedy. There are no negative images with this but is it fair?' (Norwich outreach – workshop)

The lack of discussion of cocaine other than in terms of its use by celebrities was noticeable. It seemed to be seen as 'naughty,' rather than 'dirty' like heroin. Crack cocaine – which was also largely ignored in discussion – was seen as being more similar to heroin: dirty, strong and life-altering rather than for a night out or a good time.

Heroin

Many general public participants saw heroin as 'the dirty drug' and the most dangerous of the illicit 'recreational' drugs. Its highly addictive nature was felt to leave users unable to take care of themselves, involved in theft, burglary and mugging to raise money to score and, in all likelihood, eventually dead. The difficulty in overcoming heroin addiction was acknowledged by all participants. As discussed in the section on addiction below and in the chapter on mental health, there was debate about whether it should be seen as an illness or not.

Outreach work in Liverpool, Norwich and Exeter included discussion groups with people who had been or were still using heroin, some of whom also came to the workshops in those cities. Their contribution to the discussion was invaluable, providing a more informed perspective on many of the topics. They and the stories they told were also far removed from the stereotypical 'heroin addict' depicted in the media. That it was possible to maintain a job and family life alongside a heroin habit was not something participants from the general public had considered. The presence of the past and present users helped to widen and enrich the discussion.[8]

'It is easy to get hooked to it and you might take years to get off it.' (Belfast outreach – young women)

Nicotine

A majority of participants felt that attitudes towards nicotine were hardening. Young participants were most likely to emphasise the health impact of smoking. Only those involved in the user group in London made a distinction between nicotine as a drug and smoking as its method of delivery. Smoking amongst young people was seen as a continuing problem, with adults worried about the age at which children began to smoke. One participant in the outreach group with young women in Belfast confirmed that this is something to worry about: *'*I started smoking at eight*'*. As with alcohol, the ease of access to nicotine products was pointed out, with young people able to buy under age without any difficulty.

8 We have included a separate section, in Chapter 8, outlining users' and ex-users' views on the future of control and regulation.

'I think smoking [is worst]. Millions of people die a year from smoking.' (Belfast outreach – young women)

'They are easy to get hold of as well, the shop will just sell you them.' (Belfast outreach – young people)

Drugs described as 'recreational' but not discussed

- Acid: few people mentioned LSD and attitudes towards it suggest that there was little awareness of its use or of its being a problem drug.
- Aerosol: this was named as a recreational drug by the young people in the Belfast outreach work
- Crystal meth
- Diazepam
- Ecstasy: this was not raised often and was thought of along similar lines to LSD.
- Glue
- Magic Mushrooms
- Poppers
- Prescription drugs

'Aerosol – you can just go and buy it in the shop or get it out the cupboard.' (Belfast outreach – young women)

'Crystal meth is coming in more and more now.' Liverpool outreach – Relay Project)

Why use recreational drugs?

Participants identified a wide and varied number of reasons for using recreational drugs:

- Youthful experiment
- Peer pressure
- Wanting to belong to a particular peer group
- Social isolation
- Youthful rebellion
- 'Just to see what it's like'
- No alternative activities available
- To cope with life
- Stress
- Boredom
- Easy availability / accessibility

'I didn't care, I thought I was invincible, I could take anything…you don't care about the consequences or your actions.' (Liverpool outreach – user/ex-user group)

'It is madness, excitement, fear, chaos, upset, misery.' (Exeter outreach – user/-ex-user group)

'People start because they haven't thought right through to the consequences of their actions – they just think a day or two ahead.' (Belfast outreach – young people)

'The older generation – maybe like 21 to 45, most of them started [using illicit drugs] when they were younger. Now they just stand there and drink on the street.' (Belfast outreach – young people)

Using illicit recreational drugs was associated by many participants with economic and social deprivation and, in particular, with the attitudes and behaviour of parents. The young people in Belfast spoke of being fearful of their parents' responses if they took drugs but also pointed out, as had the teachers from Exeter, that drug use was not exclusive to young people growing up in poverty: 'Middle-class kids take drugs too, for no apparent reason'. They pointed out that dealing drugs could be lucrative, something also noted by the people taking part in the Liverpool outreach work. Belfast participants commented on how dangerous it could be as well, with severe consequences for dealers as a result of actions by paramilitaries.

'Drugs are everywhere, they are not just in the council estates.' (Exeter workshop)

'Selling drugs is an easy way to make money for kids now.' (Liverpool outreach – users group)

'Some people don't need to get in to legitimate work as just involved in drugs and dealing drugs.' (Belfast outreach – young people)

'If you're shit scared of your dad you're not going to take anything.' (Belfast outreach – young people)

Many of the on-line participants talked about the pleasurable effects of drugs, such as feeling happier, more powerful or invincible. Some felt that a desire to experiment with changing the state of a person's mind is part of human nature, and several people mentioned simple curiosity. Others felt that the excitement of doing something illicit and the challenge of not getting caught played a part in making drugs attractive.

Some participants discussed drug use as a way to address problems – for example, to alleviate negative feelings, and to escape from unpleasant things such as pain, boredom, and the stresses of everyday life. Some felt that if more were understood about the risks of addiction and the other negative effects of drugs use, people would not be drawn to them. Other said that the feeling that 'it will never happen to me' meant that some people ignored the risks even though they were aware of them.

Many on-line participants cited wider social reasons that may lead to the use of illicit recreational drugs or make resistance to use difficult. They noted factors also raised in the face-to-face work such as peer pressure, a desire for rebellion, and social deprivation or lack of aspiration. Some people said people used these drugs 'because they can' – because they are available and some feel it is their right to use them.

A number of reasons were given to explain why people use illicit recreational drugs despite the risk of punishment. These included a lack of respect for the law, a feeling that the risk of getting caught is low, and a feeling that punishments are lenient and do not act as a deterrent. Addiction came up several times. People may start using drugs for some of the reasons given above but once they become addicted they either have, or feel they have, less of a choice about their drug use.

> *'[T]he pleasure they give is worth the risk. People don't like to be dictated to about such things and feel able to make their own minds up about them. Most people see the law as outdated and arcane, and hence not worthy of upholding.' (on-line participant)*

> *'People don't start taking illegal drugs – SOME people start taking illegal drugs. This is a question that could be applied to many 'illegal' or socially unacceptable situations, not only drug taking. People do it because they are human beings and have their varying reasons. Some people are in more vulnerable environments and may be pressured or learn to take drugs, some people are genetically predisposed to same, some people do it to 'find out for themselves', some people weigh up the risks and decide the risk is worth taking i.e. 'they' won't get caught therefore won't be punished by the system. People who take drugs are usually in possession of some information about what they are about to do and the consequences to themselves and to others of such action – they weigh the risks and take the choice. There is no simple answer to this question.' (on-line participant)*

> *'For the majority of users it is simply because the use of drugs is pleasurable…[t]hose that enjoy them come back for more. There is an obvious human desire for human intoxication as the widespread use of drugs and alcohol shows.' (on-line participant)*

> *'We drink coffee to keep us alert, smoke tobacco to calm us down and drink alcohol to break the ice.' (on-line participant)*

Access and availability

Illicit recreational drugs were seen as ubiquitous in every city, town and village in the UK and for anyone with a mind to buy them, the process was felt to be straightforward, though perhaps less so in Belfast, because of paramilitary control. Those who came from smaller villages suggested it was as easy to buy illicit drugs in rural areas as it was in the city. However, use was likely to be more hidden and more problematic because support and services for drug users were few and far between. This, and the perception that the price had either gone down or remained the same for some years, were seen as reasons for the increase in use in recent years. In Exeter, the teachers described how students pool their education maintenance allowance to buy drugs for sharing at lunchtime.

> *'In the old days it used to be if you didn't work you would just die, now the money comes in the post. Young people earn £40 a week and they just save it up for*

Saturday night so they can get wasted. You wouldn't have afforded that in the old days.' (Belfast outreach – parents)

'There's a very good supply network in this area.' (Liverpool outreach – community group)

'We recognise there is a drug problem for both illicit and legal drugs within Exeter, perhaps not dealt with as quickly given that there are rural associations that drugs are not a problem.' (Exeter outreach – drug users/ex-users)

Who uses recreational drugs?

The general response from a majority of face-to-face participants to this question was: 'not me'. Despite using alcohol and nicotine, most of the general public participants did not seem themselves as recreational drug users. Some comments suggest that drug use is seen as a problem that is more prevalent amongst people from less well-off environments and something that happens to their children only if they 'get in with the wrong types*'.* Some participants suggested that stereotyping drug users as being a particular and not very attractive type of person was incorrect and unhelpful.

The teachers involved said that drug use amongst their students was increasing. Those who took part in the outreach in Exeter suggested that whilst a few years ago their students were making the decision about whether or not to use drugs, they were now arriving with drug problems and accompanying educational and mental health problems. Teachers in both Exeter and Glasgow were very concerned about alcohol use. Their views reinforce those expressed by the young women in the Belfast outreach, who felt that drugs education should start at primary school age and include alcohol as well as illicit drugs.[9]

'We hear them talking about hash, not much else. They see this is ok and this is despite the fact that this is a middle class school.'

'In the 1st year I would say 25% of children have used drugs and alcohol. However, by year five and six, this will have increased to 90%.'

'I would say that the 4th year is when it peaks, this is because the young people that tend to stay on after will be less likely to use drugs.'

(All above quotes from Glasgow outreach – teachers group)

'People that take drugs now are not looked up to – people don't want to be them.' (Belfast outreach – young women)

Consequences of using recreational drugs

A majority of participants focused on the harms of using recreational drugs, looking primarily at those associated with addictive illicit drugs such as heroin. Very few participants suggested that there might be benefits to their use. Those benefits identified by general public participants were primarily associated with their use to address some form of

9 See Chapter 6 for further discussion of drugs and young people.

illness. The most frequent example given was use of cannabis for easing the symptoms of multiple sclerosis. One participant who had taken part in cannabis trials for this purpose did not find it effective.

Some participants felt there were other benefits attaching to the use of non-opiates, in particular hallucinogens, which were seen as providing altered perspectives on 'reality', which could have positive consequences for the user. Some mention was also made of the use of illicit drugs such as MDMA and LSA for treating mental illness.

Harms

Participants in the first stage of Brainbox were provided with a range of potential harms arising from drug use and asked to classify these according to:

- harm to the individual
- harm to family or community
- harm to wider society

In carrying out this exercise, participants were asked to consider prescribed drugs for mental health problems as well as legal and illicit recreational drugs. Whilst one or two participants noted that legal recreational drugs and prescribed drugs might well generate some of these problems, the focus was on illicit recreational drugs. Because of this and because the exercise focused participants' attention on harms rather than the overall consequences of using drugs, this exercise was not repeated in later workshops.

The harms provided to participants in advance were:

- Time off work
- Drug litter on streets
- Poor parenting
- Being less productive at work
- Impact on children and young people
- Addiction
- Property crime (e.g., theft, burglary, shoplifting)
- Cost of treatment
- Cost of imprisonment
- Exposure to disease
- Cost of policing
- Low self-esteem
- Mental health problems
- Harm to drug users' physical health
- Poor school attendance
- Violent crime
- Harm to babies in the womb
- Overdose
- Suicide
- Traffic accidents
- Other accidents
- Impact on families
- Health risks to friends/family of drug user

Participants argued that harms to the individual could not be isolated from those attached to the family, community or wider society. They agreed that some harms might initially seem to affect the individual alone – for example, vomiting. However, if this was sufficiently severe to be called a 'harm arising from drug use' they felt that it would also affect the

family and that anything that had a noticeable impact on the family would necessarily impact on wider society.

Participants had blank cards on which to add further harms they felt might arise from using drugs. Those identified were as follows:

- Mental illness
- Reaction
- Hallucinations
- Addiction
- Withdrawal symptoms
- Vomiting
- Weight gain
- Side effects
- Overdose
- Long-term effects
- Brain damage
- Mood swings
- Paranoia
- Depression
- Suicide
- Death
- Effect on career/ education
- Misuse
- Enjoyment
- Psychological effects
- Increased tolerance
- Finance
- Relationships
- Social exclusion
- Socially unacceptable
- Criminality
- Anti-social behaviour
- Prostitution
- Crime
- Cost effectiveness
- Medical
- Cost to the taxpayer
- Group pressure
- Bad influence
- Drugs funding

Young people from Belfast who took part in the outreach groups approached the harms of drug use from a wider perspective. They were also more likely than adults to focus on the direct health impacts on an individual of drug use, including to their physical and mental health. Young women talking about the impact of illicit drug use on the personality and attitude of friends, described them as making them 'paranoid', 'not care about the consequences' and 'disrespectful of others'

> *'My friend would come down the street and say to us 'I know yous (sic) have been talking about us.' (Belfast outreach – young women)*

> *'Health effects of a drug make it bad, if it is bad for your body then it is a bad drug.' (Belfast outreach – young women)*

Drug use or problem drug use?

Participants in the users group in London included some who had been addicted to heroin, others who were still addicted to heroin, and people whose drugs of choice were hallucinogens rather than opiates. They distinguished between using drugs and having a drug problem. This is a distinction which cuts across the licit / illicit distinction, since people might use alcohol unproblematically or be alcoholics and, similarly, some people using prescription drugs may become addicted to them whilst others can use them to what they regard as good effect. This group argued that it was possible for people to maintain illicit drug use with no detriment either to themselves or to their family or wider society, other than those arising as a consequence of buying on the black market. Participants in the

workshops also made this distinction, between the harms of illicit drugs themselves and the harms felt to result from the current system of regulation. A majority felt that adopting a health-based approach to illicit drugs could minimise regulatory harms. This issue is covered in more detail elsewhere in the report.

Asked about the distinction between drug use and problem drug use, the young people from Belfast suggested that the latter was characterised by the use of drugs to address problems, rather than for fun or experiment:

> *'Drugs can help with the problems of life, or so people think. Addiction is using drugs this way.' (Belfast outreach – young people)*

Other signs of drug use becoming problematic included theft, missing work or losing a job, and changes to personality, in particular, becoming paranoid.

> *'When you start stealing off your mum and dad, you get desperate for it.' (Belfast outreach – young people)*
>
> *'It can happen with all drugs, oh well maybe not smoking – but there is people who can't do things without having a cigarette so they have a 'drug problem' too.' (Belfast outreach – young women)*
>
> *'[Addicts are] more paranoid, desperate, changed from how they used to be.' (Belfast outreach – young people)*
>
> *'There is no difference between a drug user and a drug addict – if you use drugs you need them.' (Liverpool, ex-user)*
>
> *'You can get addicted to prescription drugs as well' (Belfast outreach – parents group)*

Drugs services

Existing drugs services were not discussed in great detail, primarily because general public participants had very limited awareness of what was available and of what quality it was. However, as noted already, many felt that more health-focused services should be available in the future.

The people involved in the user and ex-user groups provided an informed view of where services were effective and where they needed improving. Many of the points made resonate with those made by people talking about mental health services. These included a need for family support as well as support for the individual, and projects to help people who had had a long-term addiction rebuild a stable life. Several spoke of their younger years, during which most people learn the skills necessary for adult life, being lost to addiction, and others of how important it was to keep occupied now that the primary occupation of trying to score was not an option.

> *'You need support around you and you have to reach a really low point before you ask for help.' (Norwich outreach –discussion group)*

'You need support…and to be kept busy.' (Exeter outreach – user/ex-user group)

'You need to start learning new skills, life skills.' (Liverpool outreach – user/ex-user group)

'It's like being young again.' (Liverpool outreach – user/ex-user group)

'Now I am off drugs I feel like I am learning stuff I should have learnt at school.' (Liverpool outreach – user/ex-user group)

Routes into services were another issue raised by the people from Liverpool. One ex-user described how the consequences for her of not resorting to crime in order to fund her addiction were that she did not gain access to services. Again, this point is resonant with some of the comments made about mental health services. There too, one had to be in crisis before getting help. A similar situation was suggested by some users, who said that it was easier to get help and support if you supported your drug use with criminal activities and were arrested for them. If you could support your drug use by working, then support was harder to come by.

Several of the users were very critical of methadone maintenance. This issue and other priorities for future drug services are covered in more detail in the final chapter.

Conclusion

The elimination of recreational drug use is seen as impossible. Participants are very worried about the ubiquity of drugs and about the harms they cause to young people, adults, families and society as a whole. Perhaps one thing that would be helpful is a change of terminology. The idea that alcohol and heroin are recreational drugs seems somewhat misplaced, given the harms they cause to those whose use becomes problematic and the costs to their families and to society. Participants see alcohol as a more dangerous drug than heroin, yet the social and legal attitudes to the use of these two drugs do not reflect their relative dangers.

As participants discussing mental health problems suggested, a more open discussion of addiction to alcohol and the opiates might help to quieten down some of the debate around our use of recreational drugs. Participants discussed whether social attitudes might be changed in such a way that the use of illicit recreational drugs is reduced, much as use of nicotine has reduced recently, but felt that the two cases were not similar. Illicit drugs tend to be used privately, with other users. They felt that the mounting social disapproval of nicotine use depended, at least in part, on its being used openly. Then some others might not be using it, and some would be disapproving. This is unlikely to be the case with illicit recreational drugs.

7. Cognition enhancers

Introduction

The nature of discussions on cognition enhancers was different to those on mental health and recreational drugs. Participants brought views with them to debates on the latter two classes of drugs. They had their opinions on why people use recreational drugs, on the acceptability of using them and on what the consequences should be for people using illicit drugs. They knew people with mental illnesses or were aware of the recent media focus on its prevalence. The idea of healthy people using a drug to improve their cognitive capabilities was new. No settled framework for thinking about the benefits and disadvantages of cognition enhancers was in place. In other discussions, especially at the start of a workshop, participants were essentially explaining already-held views and debating with each the merits of particular positions. As the day progressed, they might change their positions following further thought or in the light of information from other participants or experts. In the discussions on cognition enhancers, participants were working out what they thought about this new class of drugs as much as explaining their thoughts to each other.

A further interesting point about the discussion on cognition enhancers is that it was the only occasion on which science as a process was questioned and the relative trustworthiness of expert opinion – meaning scientific opinion – and personal experience made evident. The absence of healthy people with personal experience of using cognition enhancers in this work – and more generally – means that participants do not have this trusted source of evidence to draw on, when thinking about this class of drug.

> *'We don't trust the experts. We'd trust personal experience…someone who has actually taken them and knows.' (BB2)*

This felt like the start of a conversation that should continue, with some of the questions raised in this chapter explored in more detail and more depth.

This chapter does, however, provide initial insight into many issues that might arise in further dialogue. It looks at participants' views on the use of cognition enhancers by healthy people and by people with mental health problems associated with ageing. The use of cognition enhancers by young people, whether for enhancing 'normal' young people or for treating children with attention deficit hyperactivity disorder is covered in the following chapter, on Drugs and Young People. Despite disquiet about the potential social and individual consequences of cognition enhancer use by 'normal' 'healthy' adults, a small majority wished to protect freedom of choice, with the proviso that a lot more research should be done before this class of drugs could be made legally available.

Attitudes towards enhancement

Participants' views on acceptable and unacceptable methods of enhancing the human body are complex. They made two distinctions that are important to understanding these views. The first is between treatment and enhancement. Participants debated the appropriate balance between drug and other forms of treatment or support, but the great majority did not question that this class of drugs has benefits for mental health problems associated with ageing or for young people with ADHD. Using the same class of drugs for enhancing the cognitive functions of 'normal', 'healthy' people generated considerable debate. This debate was organised around a second distinction between 'natural' and 'unnatural' forms of enhancement.

Natural enhancements mentioned by participants included vitamin supplements, herbal preparations, a good diet and plenty of exercise, hiring a tutor to help your child with school work or doing brainteaser puzzles or exercises to improve memory. These make you feel good about yourself or the way you look after those you love. They are, as one participant said, 'advertised as being about a healthy lifestyle*'.* Unnatural enhancements include pills to improve cognitive abilities and cosmetic surgery, and are treated with suspicion. Whether there are wider social consequences arising from use of enhancements seen as natural was discussed.

A few participants felt that taking drugs to enhance performance was acceptable, providing it did not harm the taker or society more widely. As long as people were aware of and willing to accept any associated risks, this was seen as a personal choice. But only a very small minority expressed this view. The predominant response was that taking drugs to enhance performance, whether physical or cognitive, was wrong, for reasons that are explored later in this chapter.

> *'If it isn't harming anyone else or society more widely then why not?' (Glasgow workshop)*
>
> *'It is personal choice if people want to take the risks.' (Glasgow outreach – ADHD parents)*

Framing the debate

The way in which discussion on cognition enhancers is framed is crucial to attitudes. Some of the questions asked in the Glasgow workshop help to illustrate this. Participants were asked a series of questions, the results to which are shown in the following table:

Question	**Response (%)** *PM (AM)*	
If you could buy a pill over the counter that helped you to overcome the effects of normal ageing on your memory, would you take it? (e.g. something that would help you remember where you had put your keys).	Yes: No: Unsure:	42 (38) 38 (29) 19 (33)

Question	Response (%) *PM (AM)*	
If a pill as safe as aspirin was developed that improved your ability to solve problems would you take it?	Yes: No: Don't know:	67 (64) 33 (24) 0 (12)
Do you think it is acceptable for healthy adults to take drugs (as safe as an aspirin) to improve problem solving skills and concentration?	Yes: No: Don't know:	24 (28) 72 (60) 4 (12)

Changing the stated reasons for using a cognition enhancer alters people's views of their acceptability. Responses vary, for example, according to whether the drugs are said to be helping solve problems, or helping to overcome the irritations of normal ageing processes. The language used also affects responses, for instance introducing the word 'drug' as a replacement for 'pill.' Whilst this data has no statistical significance, it does help to illustrate the importance of teasing out the differences between attitudes towards enhancement as such and the way these are complicated by other factors. These can include perceptions of appropriate and inappropriate use of drugs, the methods of delivering a substance into the body, marketing, and packaging. In this project,the question was posed in terms of drugs, as these were the over-arching theme of our work.

The way in which delivery of a substance into the body impacts on such views can be illustrated by a further question, asked in discussion. Participants were asked if their views might change if cognition enhancers could be added to, for example, broccoli. This was seen as much more desirable. Vegetables – and perhaps broccoli in particular – are seen as beneficial in themselves and the idea of feeding 'enhanced broccoli' to one's family was viewed more favourably than dosing your child with a pill before they leave for school. Enhancement delivered in this way takes us into the context of leading a healthy lifestyle.

Drinks were also discussed. Nearly 80 per cent of participants in the Glasgow workshop drank tea, coffee or Red Bull. The briefing information noted that caffeine was a cognition enhancer. When it was suggested to participants that a majority of them were already using a substance with effects very close to the drugs currently available off-prescription to those who wanted them and to Modafinil, researched by one of the experts at this workshop, they argued that the long history of their use meant their side-effects were well understood, and that the social context surrounding use of coffee, tea and Red Bull placed them in a different category.

> *'Tea and coffee have been around for ages – it's a cultural thing.' (Glasgow workshop)*

Overview of main concerns

Six main issues were raised in relation to the possibility of cognition enhancers becoming widely available for use by healthy adults:

- **Unwanted or unknown effects**: this relates to a general fear of addiction and also to the absence of information about the long-term effects of using cognition enhancers. Whilst

side-effects appear to be negligible, according to existing research, participants felt that the current state of knowledge was not an adequate basis on which to make decisions about how this class of drugs should be regulated for use by healthy people

- **Devaluation of 'normal' achievements**: the effort and motivation involved in learning are seen as having an intrinsic value that would be reduced by use of cognition enhancers. This argument was applied in particular to young people but was also raised in relation to adult use

- **Equality**: participants were concerned that cognition enhancers might further increase existing social inequalities

- **Pressure to use**: participants felt that use of cognition enhancers by healthy adults would exacerbate what they saw as an already over-competitive culture, with people needing to use cognition enhancers, even if they would prefer not to, in order to 'stay in the game'

- **Control**: drawing perhaps on some of the debate in the media around the use of methylphenidate (Ritalin) to control ADHD, participants expressed the fear that cognition enhancers might be used to control people's behaviour

- **Personality change**: participants worried that long-term use of cognition enhancers might lead to people's personalities changing and that you would no longer know '*who you were talking to'*. This was associated with notions of deception: they felt that people might gain jobs on the basis of chemically enhanced cognitive abilities, to which they were *not really entitled'*.

These concerns dominated discussions of cognition enhancers in all face-to-face events, but people were also anxious to protect civil liberties, as they had been in discussion on other drugs. In general, participants felt that adults should have the right to make their own decisions about whether or not to use existing and new drugs. A few participants were more open in their responses, seeing many of the concerns raised as part of a wider 'anti-drug' sentiment and arguing that, providing they were effective and safe, they should be available for people to buy without prescription. Many felt unable to make any firm judgement, given their present limited knowledge.

> *'Drugs get an anti-drugs sentiment. People jump to the wrong conclusions, and they are often negative.' (Glasgow workshop)*
>
> *'More research needs to be done into the long-term effects before they are licensed for wider use. I don't really have any principled objection to their use – there are arguments that raising the IQ of the population as a whole would result in a happier, more wealthy society, which has to be good. I suppose my concern would be their use for coercive reasons – which would, I think, be inevitable to some extent, given the increasingly authoritarian direction in which government is heading.' (on-line participant)*
>
> *'Do we ignore or use the information that we discover?' (Glasgow workshop)*
>
> *'It's just the fact that I don't know enough about them so I'm wary.' (BB2)*

'They're very much an unknown quantity. We don't know what they are capable of or what extremes they'll be used for." (BB2)

Benefits

The benefits of cognition enhancers for people suffering from conditions such as dementia and ADHD were largely undisputed and a great majority did not question their use for these purposes.[10] As noted already, the majority drew a clear line between their use for alleviating identified medical problems and their use for enhancing the cognitive capacities of 'normal', 'healthy' people. They felt that their use without defined medical need would be a further example of the 'quick fix' society, on the basis of the six concerns noted above. For participants it appeared that the level of acceptable risk and side effects depends on whether they are being used to treat a diagnosed medical problem or for enhancement of a 'normal' state.

A few students saw some benefits to 'healthy' people using enhancement, including improved performance and better exam results. However, they, like the majority or participants, felt that there were more disadvantages than benefits associated with the use of cognition enhancers by 'healthy' people.

'Is it cheaper to use drugs? Would we be using them as a sticking plaster?' (Glasgow outreach – students)

'It is a sticking tape for making bad society better, it is a fake fix.' (Glasgow outreach – students)

Cognition enhancers and healthy people

Unwanted or unknown effects

This was a major concern for all participants. In two face-to-face events (Glasgow and Brainbox 2), experts explained that current research suggests that the side effects of using cognition enhancers (modafinil) are minimal and pointed out that in her own research the placebo appeared to generate more side-effects than modafinil itself. However, participants felt that the consequences of long-term use in particular remained unknown and that these needed to be understood before they could be licensed for use by healthy adults.

Participants asked about the differential effect of enhancers on people of different 'natural' intelligence and what the consequences might be of stopping after long-term use. Would people retain the knowledge they had gained, return to the same level of intelligence they had prior to using cognition enhancers, or even return to a lower level? It was explained that these things were not yet known and that, on the issue of differential effects, the research findings were not consistent. One participant suggested that the use of steroids in bodybuilding might serve as an analogy: people using steroids to increase muscle bulk did not lose muscle gained if they stopped using the steroids. Similarly, he did not feel that knowledge gained as a result of greater focus or memory capacity resulting from use of

10 See section below on Cognition Enhancers and the Ageing Brain

cognition enhancers would be lost if use was stopped. This analogy did not have much impact on other participants' views.

Addiction was a further worry. The consequences of dependence on any drug – recreational drugs or prescribed mental health drugs as well as cognition enhancers – were a constant theme throughout all discussions. The cost of addiction for the individual and society were seen as great and the prospect of introducing a further opportunity for addiction was not welcomed. Research suggests modafinil is not addictive. But participants argued that addiction could be psychological as well as physical and that success achieved as a consequence of using enhancers might lead a person to think they were not able to succeed without them.

> *'What will the side effects be, the long-term effects? An addiction can be psychological as well as physical.' (Glasgow workshop)*

> *'If you take them and then stop, do you forget what you learnt when you took them? Is there a come down afterwards?' (Glasgow workshop)*

Devaluation of 'normal' achievements

Effort and motivation were seen as intrinsic to the value society places on knowledge and learning. Using cognition enhancers in education or employment was seen as devaluing learning, turning it into a commodity that could be acquired more easily by those who had the resources to buy the drugs. Facilitators pointed out that these inequalities already exist, with some able to afford tutors for their children. However, the participants' response was that an already unequal playing field was not a reason for introducing a further means of increasing inequality. Rather, they argued, the reason why people need to hire tutors in the first place needs to be addressed, which means examining the inequalities inherent in the education system.

Participants' emphasis on the need to understand and rectify longer term and structural problems and avoid superficial solutions – which participants felt cognition enhancers were – was common throughout the project as a whole.

> *'You need to work for what you do.' (Glasgow workshop)*

> *'How does the individual feel about her own achievements if she has been enhanced? This is about authenticity.' (BB2)*

> *'The danger of allowing cognition enhancers for academic or employment use is in there being too much emphasis on peoples' abilities rather than on their intrinsic value as human beings. People with disabilities deserve equal opportunity and respect and for able people to consider their value is too bound up in their success and achievements implies that there is a hierarchy of worth based only on achievement. What makes us human is our ability to love ourselves and each other unconditionally. Conditional factors should come later in our self-valuing. Let's keep the emphasis on the Human Being, not just on the Human Doing.' (on-line participant)*

> *'I feel that it is unethical, it's cheating and you have an unfair advantage.' (BB2)*

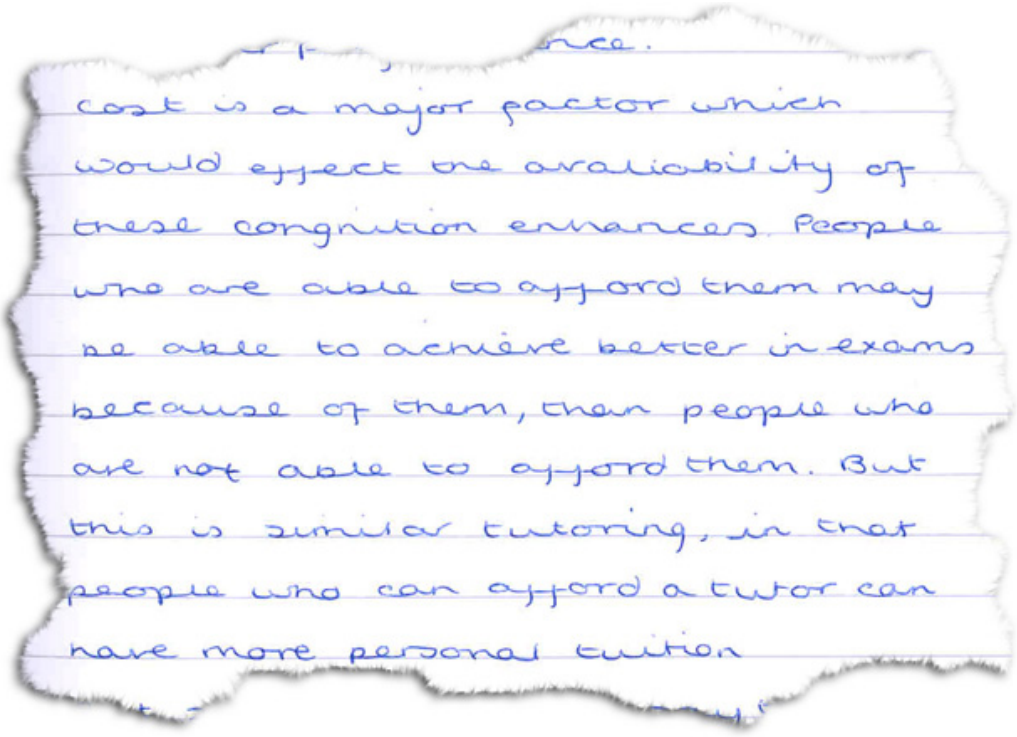
Equality

As noted above, participants were concerned that cognition enhancers might further increase existing inequalities. Despite being aware that modafinil could already be bought over the internet, participants felt that its current illicit use did not constitute an argument for allowing its legal purchase by adults in the UK. They acknowledged that restrictions on legal use might increase the inequalities about which they were concerned, since the number of people with internet access and the money and inclination to try modafinil would probably grow. However, a majority felt that it was in principle wrong for cognition enhancers to be licensed for use by healthy adults.

> *'It would depend a lot on how much you could afford – although it may improve the quality of your life it would make inequalities worse.' (Glasgow workshop)*

> *'You need a social answer to social deprivation' (Glasgow outreach – teachers)*

PAGE FROM DIARY KEPT BY YOUNG CARER ATTENDING BRAINBOX.



Pressure to use:

Competition in school and work was seen as constraining people's choice about whether to use cognition enhancers, increasing pressure and, in effect, forcing people to use them. This debate relates to the view of the majority that learning has an intrinsic value. Competition to achieve is seen as detracting from this value, since it measures individual achievement in terms of its relation to the achievement of others, rather than on the capacities of that individual. Knowing that certain cognition enhancers are already in fairly

widespread use amongst college students in the US, primarily modafinil, and that Ritalin is becoming increasingly used in the UK, did not seem to dent participants' negative response to them. As in the discussions on equality, their arguments are principled, rather than pragmatic, being based on what they see as right, rather than on addressing an existing state of affairs.

> *'People will have to compete…there will be a pressure to take them.' (Glasgow workshop)*
>
> *'If everyone was falsely getting ahead, they will have to take it and you will get dragged along and would feel that you had less choice in taking it.' (Glasgow outreach – student group)*
>
> *'You are going to have to take them to keep up…you either join them or you are left out.' (BB2)*
>
> *'I think if your kid's friends took this drug, parents would feel under pressure from their kids to give it to them even if they didn't want t, in case you felt you were holding your kids back.' (BB2)*

Control

Drawing perhaps on some of the debate in the media around the use of methylphenidate (Ritalin) to control ADHD, participants expressed the fear that cognition enhancers might be used more widely to control people's behaviour, or to pressurise them to perform at high capacity at all times.

> *'It has Nazi overtones.' (Glasgow outreach – teachers)*
>
> *'We will be creating drones.' (Glasgow outreach – teachers)*

Yet despite this, the teachers in the Glasgow outreach work felt that making sure that choices were informed was sufficient to allow people to decide whether they wished to take enhancement drugs.

Personality change

Some participants felt that the long-term use of cognition enhancers might lead to personality changes and that others would no longer know 'who they were talking to'. This was associated with notions of deception: they felt that people might gain jobs on the basis of chemically enhanced cognitive abilities, to which they were 'not really entitled'. Others felt that these drugs would lead to loss of artistic and creative skills.

Cognition enhancers and the ageing brain

Alzheimer's disease and dementia more generally were seen as pressing social problems. The increasing incidence of Alzheimer's and its appearance in younger people were cited as reasons for focusing research on its underlying causes and on developing more effective drugs to delay its progress in the early stages. People saw great benefits in the

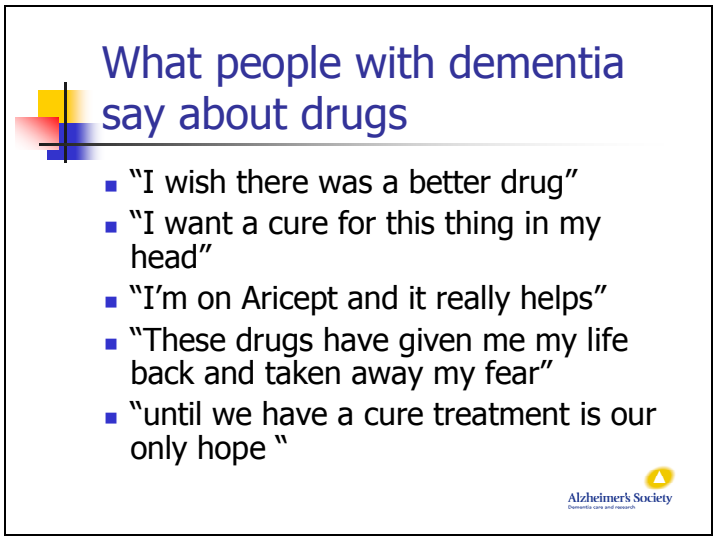
use of cognition enhancers to treat conditions such as dementia. As noted in the chapter on mental health, the value of drugs to help stabilise people with more severe or debilitating problems was not questioned.

However, consistently with the overall attitudes towards drugs displayed throughout the project, many people felt that drugs should only be used if psychological and social approaches to alleviating symptoms such as distress and confusion had first been exhausted. Participants' concerns here were very similar to those raised in the discussion of other mental health problems. They asked whose interests were being served by the use of drugs. In the Merthyr Tydfil workshop in particular, which focused on mental health, it was suggested that older people were 'drugged up' to keep them quiet and make them easier to manage. A primary reason for this was seen as insufficient resources being dedicated to the care of older people.

> *'Prevention is more important because old people are just given drugs to sit in the corner. The government don't want to put money in.'*
>
> *'Some of the ladies I work with are drugged.'*
>
> *'They tell you they can't do anything for you and then they give you a pill.'*
>
> *'The drugs aren't for the Alzheimer's, they're just for the control.'*
>
> *'A lot of nursing homes, they're sat around, staring at the TV all day.'*
>
> *(All quotes from Merthyr Tydfil workshop)*
>
> *'If you go to a doctor you're just going to be prescribed something when there's actually so many other approaches.' (BB2)*

The slide below, taken from the presentation prepared by The Alzheimer's Society, helps to illustrate, from the user's perspective, some of the benefits of drugs as well as the desire for a cure and for improvements in the existing drugs.

SLIDE TAKEN FROM THE PRESENTATION PREPARED BY THE ALZHEIMER'S SOCIETY



Participants in the outreach group held at a residential home for older people were more pragmatic about the use of drugs to alleviate the symptoms of ageing. Asked if they would be willing to try a drug that helped them to remember things like where they had left their glasses, a majority said they would '*have a go'*. All participants currently took a range of drugs, though most did not know what these drugs were and did not question whether this was the best thing for them to do: '*I just take it.*

The problem of loneliness amongst older people was raised in a discussion of the effectiveness of drugs for depression. Some participants had used these drugs, with varying degrees of success. Loneliness was seen as one of the primary causes of depression among the old, along with restrictions on activity arising from physical incapacities. This suggests, as an employee of the residential home said, that addressing older people's mental health problems with the use of cognition enhancers might have adverse consequences if their physical health remained poor. She suggested they might become more aware of their physical incapacities and grow more depressed. This view was shared by some of the on-line participants, though they did not feel that frustration with physical incapacities would be sufficient to eliminate the benefits of cognition enhancers. The primary consideration would be the freedom of the individual to choose whether to start, or continue. use. Making sure that investment in improving the physical health of older people kept pace with investment in developments in cognition enhancement was seen as crucial by some participants.

> *'There's a huge difference between using a drug to treat an ailment and for routine performance enhancement. Mental alertness in older people probably improves the quality of their lives, though not necessarily. I can think of instances where an older person complained that her body wouldn't let her die, even though she was tired of life and the discomforts of old age. So perhaps the medical profession should stop thinking that it is omnipotent and omniscient, and start to respect the desires, wishes and needs of their patients.' (On-line participant)*

However, an alternative interpretation suggested was to ensure that older people are not isolated and growing lonely. Many participants felt that making drugs available to treat distressing symptoms and heighten cognitive capacities could help to lessen the frustrations caused by physical ageing.

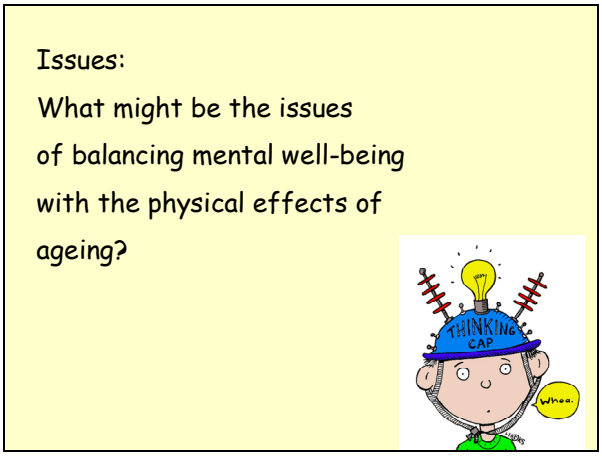
> *'Loneliness is a killer.'*
>
> *'I think the loneliness is worse than the illness.'*
>
> *'I get depressed because I can't do what I want to do.'*
>
> *'I got depressed after my stroke because it would not get better.'*
>
> *(All above quotes from Wales outreach-older people)*
>
> *'There is no reason why the physical effects should not be reduced as well. But even if someone is bedridden, it certainly helps if they are able to enjoy cognitive pursuits, like TV, reading, and can have a sensible discussion with their carer. Having cared for a parent with multi-infarct dementia I fell there is absolutely no*

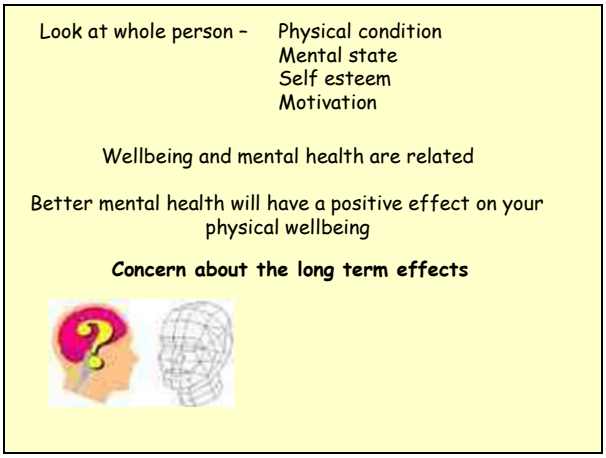
question that the treatment of dementia would be a 100% plus with no downside.' (on-line participant)

The value of drug therapy for people with dementia was also raised in the Glasgow workshop on cognition enhancers. Participants felt that, for older people in particular, improved mental health resulting from use of cognition enhancers would benefit physical health too, rather than generating further distress because awareness was increased. A few participants in the on-line work questioned the overall focus on treatment, urging greater attention be paid to the causes of age-related mental illnesses. Like others in the project, they emphasised too the relationship between mental and physical well-being.

'There you go again! 'Treatment' of diseases is a bad thing: they should be cured, and the likelihood with Alzheimer's is that it is an environmental/lifestyle disease, that will decline when more is known. Looking for 'treatments' squanders research resources that should go into finding the true cause and its cure! Sound body and sound mind go together so anything which will improve either will be good for both.' (on-line participant)

The two slides below summarise the response of Glasgow participants to the issue of balancing mental well-being and physical ageing. They urge a holistic approach, where self-esteem and motivation as well as mental state and physical condition are important and related. The concern about the long-term effects of drug use expressed by younger participants was not shared by the residents in the outreach work, all of whom were aged over 80.





It would mean a better lifestyle.' (Glasgow workshop)

'My mum has dementia, having experienced first hand the effect of brain deterioration and experienced the distress, I can understand someone wanting to take drugs. But I want to take drugs as a last resort.' (Glasgow outreach – teachers)

Cognition enhancers and work

We have already noted participants' resistance to the use of cognition enhancers in employment. Only a minority of participants felt that employees should be at liberty to use these drugs if they wished, and only then if safeguards were in place. Views were divided on whether employers and schools should be allowed to test for the use of cognition enhancers. Some appealed to the arguments about fairness and equality raised earlier in this chapter. Others felt that as long as the drugs were safe and legal, schools, but not employers, should be allowed to test their students, to stop cheating. Others argued that testing would be an invasion of privacy and that, if the drugs were legal, there would be no reason to conceal their use. Some on-line participants raised the question of access to test results.

> *'I just don't think they should ever become widely used, so yes, I think employers should be able to test for them, as they can today for illegal substances.' (on-line participant)*

> *'Just like testing people for illegal drugs now, it is an invasion of their privacy and against their human rights. If someone doesn't perform to the job's standards they should be dealt with for that fact, whether they use a drug or not should not matter, and using a test result to get an employee to stop taking or start taking a drug is discriminatory and in violation of their freedom to choose what they do with their body and mind.' (on-line participant)*

This slide below taken from a presentation by participants in the Glasgow workshop, illustrates a preference for freedom of choice regarding adult use. But it also highlights a different attitude to employers having the right to require people who got a job as a result of using cognition enhancers to continue using them.

SLIDE TAKEN FROM A PRESENTATION BY PARTICIPANTS IN THE GLASGOW WORKSHOP

In addition to the general discussion, there was some debate about cognition enhancers for people in professions demanding high levels of concentration. Opinions were very split. This seems due at least in part to the limited time that participants had to review information on the existing research on the effects of this class of drug. It is not possible to say how more information would have impacted on participants' views, which may have remained the same even with more knowledge.

The idea of the military using drugs during operations, including amphetamines and cognition enhancers, shocked many participants, perhaps because of the association of drugs with loss of control. Experts had explained that cognition enhancers might decrease impulsive behaviour, increase reflection, focus and problem-solving skills, all of which might be of benefit to soldiers. This did not convince a majority of participants in Glasgow and Brainbox 2, however. One ex-soldier in particular found abhorrent the idea that he might be working alongside people who were using drugs. Some argued that individual soldiers would not have a choice about whether to use them and that this was a reason for disallowing them by the military as a whole. Only a very few participants saw any benefits.

> *'I'm all for it- soldiers should be allowed to take concentration drugs.' (Glasgow workshop)*
>
> *'We're interfering with nature here. These poor guys who go out to the front line with an implication that they might lose their jobs [if they refuse to take cognition enhancers] – I'm absolutely horrified.' (BB2)*

Conclusion

The discussion on cognition enhancers was different to those on the two other classes of drugs looked at in this project. The overall conclusions was that more research needs to be done before policy can be made about their use by healthy people. Protecting freedom of choice was seen as important. But without a good understanding of the long-terms consequences of use on health and on society overall, participants felt that the healthy adults should not have the choice to use cognition enhancers. They raised a number of concerns regarding the impact of their widespread use. Mounting pressure to use enhancers to succeed in a competitive society, devaluation of the intrinsic worth of learning, and taking the focus away from more fundamental issues such as inequalities in the education system are just three of these concerns.

The treatment with cognition enhancers of mental health problems such as dementia and ADHD is not unquestioned, but it does meet with majority approval. Again, however, improving the social and educational services available to help and support older people with illnesses such as Alzheimer's Disease, and children and families coping with ADHD, are seen as essential.

8. Drugs and young people

Introduction

Young people's drug use was a recurrent theme throughout this project and, in particular, in discussions about recreational drugs and cognition enhancers. One workshop, in Belfast, focused solely on drugs and young people. In the workshops and outreach groups that focused on drugs for mental health, problems amongst young people, such as anorexia, self-harm and the rising incidence of depression, were raised but not discussed in any detail. Events focused on cognition enhancers included discussion of attention deficit disorder amongst young people as well as their use by 'healthy' young people.

The young people who took part in the project had a very high awareness of drugs and some experience of their use, which was either mildly positive or mildly negative. No extreme experiences, either pleasurable or disturbing, were recounted. The young people from Belfast did not see drug use as something to show off or be proud about. Terms such as 'losers' and 'wasters' were used to describe friends and acquaintances who used recreational drugs, including alcohol, on a regular basis.

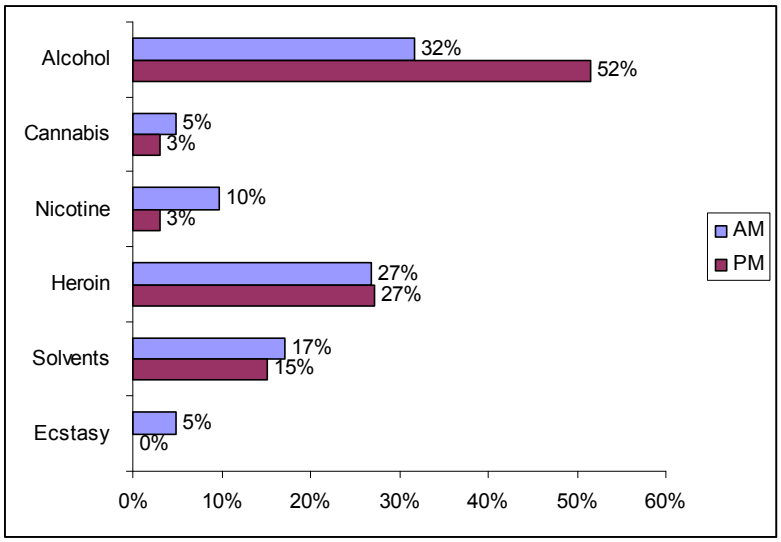
This chapter focuses on some of aspects of drug use which are seen as particularly relevant to young people. It should be read alongside the chapters on recreational drugs and cognition enhancers, which also include discussion of young people and drugs.

Why focus on young people?

Drug use by young people was seen as being different from drug use by adults, by all participants, for a number of reasons. First, young people's brains are still developing and the effects on them of drug use may differ both immediately and in the longer term. Harm to future health was one of the primary reasons given for restricting drug use amongst young people. Some felt that the legal age for alcohol use should be raised to 21. Teachers, in particular, raised concerns about the longer-term consequences of what they saw as a growing problem of alcohol use amongst 12 and 13 year olds. For prescribed drugs, informed consent is more problematic with younger people. It may take more time, for example, and young people may find it more difficult to take into account the future consequences of using any drug, whether prescription or recreational. Finally, an issue raised by many participants and discussed in some detail by teachers was young people's greater vulnerability to peer pressure.

The chart on the following page ranks the harms associated with different recreational drugs, as seen by people in the Belfast workshop. Whilst this has no statistical significance it does reflect the views of participants across all locations who discussed this issue. One possible explanation for the higher afternoon vote for alcohol as the most harmful drug is that by then, the audience had heard teachers' explain that alcohol use by young people is widespread, causing great damage now and having serious implications for the future.

WHICH OF THESE DRUGS DO YOU THINK IS MOST HARMFUL TO YOUNG PEOPLE AS INDIVIDUALS?



Belfast, (n=41 (AM) n = 33 (PM))[11]

Recreational drugs

Prevention

Many participants in both on-line and face-to-face work thought that it was impossible to prevent all young people from taking drugs. Rebellion and experimentation were seen as part of growing up and for some young people this would mean using drugs. The inevitability of drug use by some people, whether young people or adults, was behind much of the support for a health based or harm reduction, rather than punitive, approach, to drug use.[12]

> *'You can't tell kids not to get involved in drugs – they have to make their own decisions.' (Exeter workshop)*
>
> *'If you knew someone was taking drugs you could tell them to go and get help but that is as far as you could go – you can't force people not to take them.'*
>
> *'Jeremy Kyle tries to force people and that probably doesn't work.'13 (Belfast outreach – young people)*

Many felt that the most effective way of discouraging the maximum number from using drugs was to address the social and environmental factors that might make a young person more vulnerable to drug use. Some participants in the on-line work characterized this in terms of support from parents and the wider community, providing positive role models,

11 The drop in base numbers between the morning and afternoon voting is due to the younger participants (under 16) leaving at lunchtime.

12 The term 'harm reduction' was used by people involved in some of the outreach work with drug users and ex-users but not by general public participants. However, many described features of a harm-reduction approach in their discussions, without using this term.

13 The Jeremy Kyle Show is a programme shown on ITV.

teaching personal responsibility, reducing inequality, tackling gangs and providing a creative and loving environment.

> *'Giv[e] young people a decent life with enough love and care.' (on-line participant)*

Some participants in the on-line work felt that the most effective way of preventing harm from drug use was to end prohibition, particularly of drugs seen as less harmful, such as cannabis. These drugs would be distributed as alcohol and tobacco are today, with retailers losing their licence if they were found supplying to young people. The benefits attributed to this, and the disadvantages, are discussed in more detail in the chapter on control and regulation. And end to prohibition was not supported by a majority of participants.

Education and information

Effective education, information and services for both parents and young people were seen as vital. 'Education' was often the first response to the question of how young people could be discouraged from drug use. However, as currently delivered, drugs education is not seen as very effective, for a number of reasons. The approach is seen as 'more telling than listening', and many feel that insufficient attention is given to the emotional and social factors that might lead young people to try drugs and, possibly, progress to problem drug use. The young women from Belfast felt that the purpose of drugs education should be to help them to make decisions, rather than scaring them into making what adults felt was the right decision. Young people in one of the Belfast outreach groups had recently completed an Open College Network level 2 Drugs Awareness training course. Asked about this, one described it as '*just common sense*' about drugs. The general view was that these courses don't tell you anything you don't know already. Perhaps the clearest message to emerge about drugs education is that no one single approach will be effective for all. Using a variety of approaches, messages, media and people and situating the information within the specific local context is seen as important.

> *'Once you are grown up you can make your own decisions, but children need to be helped to make decisions because they don't know anything about the dangers.' (Belfast outreach – young women)*

A majority of participants saw scare tactics, moralising or 'just say no' approaches as ineffective, primarily because they are often at odds with young people's own experiences. Many suggested that the police should not be providing drugs education and that greater involvement of users, ex-users and peers would bring more success. The one group that disagreed with this was the young people's group in Belfast. They thought that shock tactics worked as a warning to those who had been caught.

> *'The best way to get people to take drugs is to tell them not to, especially young people' (Belfast outreach – young women)*

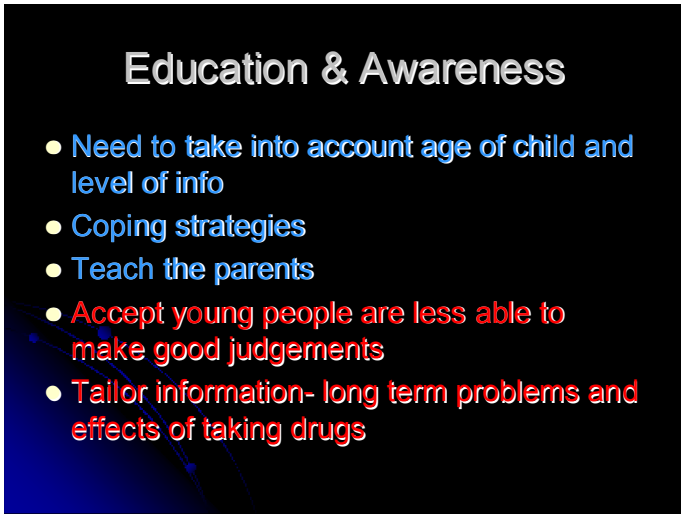
> *'If someone gets caught taking drugs, they should be held in custody for 48 hours, so that they had a chance to get scared and their mum and dad should be involved.' (Belfast outreach – young people)*

Many feel that good drugs education will provide balanced information that is honest about the benefits that may attach to recreational drug use, as well as the harms. For younger people, these could include belonging or wanting to belong to a particular social group, providing an escape from pain, depression, abuse, bullying, worry or loneliness, the pleasure of rebellion, association with admired artists, writers or musicians, freedom from the usual restrictions of school, homework and helping in the house, being able to stay up all night dancing (or studying), heightened sexual pleasure or just straightforward experimentation with perspectives on the world. Acknowledging the benefits may help to validate information about the harms too, since this may fit better with young people's own experience of drug use – their own or their friends – and thus make the messages more acceptable.

> *'They should be effectively and TRUTHFULLY educated about the effects of drugs and the dangers of drug misuse. This would consist of educating them that some use of drugs isn't necessarily a problem, only misuse/overuse. Furthermore it would consist of not lying to people, drug education is currently quite ineffective because it says things like 'just one ecstasy tablet can kill' which is barely true and which people will realise isn't true as soon as their mate Steve's mate Dave takes one and doesn't die, from that point on they won't trust anything they were told, even the true bits.' (On-line participant)*

The slide below, taken from a presentation developed by participants in the Belfast workshop, outlines their views on some of the elements of good drugs education. These include ensuring that the level and type of information provided is appropriate to the age of the child, including ways to develop coping strategies to help young people make decisions, and acknowledging that they may be less able to make 'good judgements' than adults. Educating parents as well as children is also seen as important. Including discussion of alcohol in education is also important.

SLIDE TAKEN FROM A PRESENTATION BY PARTICIPANTS IN THE BELFAST WORKSHOP



More creative approaches

Many people felt that educational approaches needed to be more creative and draw more widely on the knowledge and experience of people who have used drugs, and on peer education. Teachers in particular emphasised that young people are more likely to be influenced by their peers than by teachers or other adults. Delivering information and education in settings other than school is seen as likely to be more effective.

In Brainbox 2 there was much debate about the value or otherwise of ex-users being involved in drugs education. A few participants felt that if education were provided by someone who had been addicted to an illicit drug but had continued to work and maintain a family, the message that 'drugs are bad for you' would not be adequately conveyed. A majority of participants argued that young people were more likely to take notice of education that gave a balanced perspective and encouraged them to make their own decisions. They felt that young people were more likely to discount anything they felt was not 'genuine' or based on real experience, and that user groups should be much more closely involved in both the design and delivery of drugs education.

A very small number of participants felt that drugs education was ineffective because it did not adopt a sufficiently harsh tone, emphasising the dangers and ramifications of using illicit drugs. This view was not widely shared.

> *'Education isn't working – it's too soft.' (Liverpool workshop)*
>
> *'[Use s]hock tactics – pictures of people injecting into own eyelid.' (BB2-IL)*
>
> *'I was in jail and I saw a guy coming off heroin – if you saw that you wouldn't go near it.' (Liverpool workshop)*

One final element of prevention that is perhaps not usually thought of within the context of drugs education, is nagging. In the Belfast workshop, young people appeared at times to be nagging any of the older participants they had seen smoking during breaks to stop. Whilst the effectiveness of this approach was not explored in any detail, it was seen as *'getting the message through.'*

Advice from users and ex-users

The views of people who had used or were still using drugs are particularly important, since many will have started using them while young. The presentation prepared by people from the Relay Project in Liverpool, and given at Brainbox 2 by two of its members, outlines some additional suggestions for supporting children and young people, both in general terms through education and, more specifically, to help those whose parents are having problems with drug use.

Their suggestions look more widely at the place of children and young people in society today and the need to value and support them. They argue that a majority of people who use drugs do so to cope with childhood traumas. Investing in children's services and focusing on the prevention of these traumas is seen as a way of helping to minimise problem drug use in later life.

The specific suggestions made by people involved with the Relay Project include removing the stigma and guilt associated with parental drug use. This can affect children deeply and arouse fears, including that their parents may be taken from them or put into prison. They may fear their parents' death. They may also resent their parent's habit and the stigma and guilt that attaches to them as the child of an addict. Providing confidential support services for children and young people and support to help families stay together are seen as crucial in helping to address these problems. Ensuring that social workers understand and are trained in how to provide this support is a fundamental aspect of these services.

The Relay Project presentation included suggestions for improving drugs education too. Many of the points have been discussed above, including inviting ex-users and drugs-workers to take part in drugs education, rather than the police, and starting education earlier – they suggest at age seven. They emphasise too the need to focus on prevention and harm reduction, and taking a 'more open and honest approach than 'DON'T DO THAT''. Additional suggestions include:

- having drugs liaison workers in schools where there are high levels of risk
- having specially trained children's counsellors in schools to provide support in coping with difficult situations involving family, relationships, peer pressure, abuse, bullying and other personal issues

Trusted sources

Discussion of the involvement of ex-users and users in drugs education underlines that the messenger can be as important as the message. Many of the young people involved appeared not to trust what teachers said. They were not felt to know much about drugs and, as remarked earlier, they could be seen as hypocritical, preaching abstinence from one type of recreational drug whilst using another perhaps more harmful, drug themselves.

Doctors were not seen as a necessarily trustworthy source of information either, especially by young people. Young people did not see them as having any personal understanding of addiction. Some workshop participants felt that users would not be able to talk about having a drug problem with their GP for fear of being struck of the GP's list. Others felt that this was less likely to happen now. In general, however, GPs were seen as insufficiently informed about drugs and addiction. But their support and help were seen as important, so educating GPs may also be an important aspect of increasing the effectiveness of drugs education generally.

> *'Doctors haven't experienced being on, say, heroin.' (Belfast outreach – young people)*
>
> *'[Doctors] can't tell you what it's like to be on them.' (Belfast outreach – young people)*

A majority of the young people said they would place most trust in the advice of someone who had used drugs and survived, since they would know about the effect of drugs and the potentially devastating impact on the user's life. Other trusted sources included a local

drugs advice centre (Forum for Action on Substance Abuse, in Belfast) and people at the local community centre.

Some of the young women in the Belfast outreach work had used the Ask Frank website as part of their drugs education and were generally positive about it, again focusing on the information being seen as 'true' and also on the extensive range of information provided.

> *'You can ask questions to it and they tell you the truth.' (Belfast outreach – young women)*

> *'I actually went on to it and it was mad, it was just information about every drug.' (Belfast outreach – young women)*

People taking part in the London outreach user and ex-user group echoed many of the points made by people from the Relay Project and the young people regarding the need to involve users.

> *'The most educated are the least heard.' (London outreach – users group)*

Information for parents

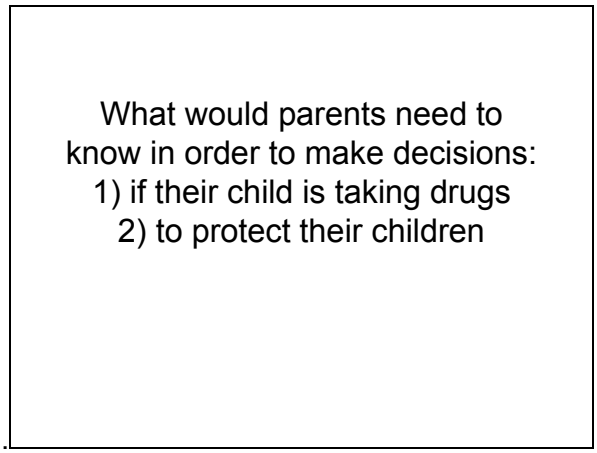
The anxiety of parents about the availability of recreational drugs and the prevalence of their use amongst young people was very clear in the face-to-face work. Parents were seen as needing different information at different times, depending on whether they were seeking to learn about drugs generally or had discovered their child was using recreational drugs. Many felt they would like to know more but were not sure where to go for accurate advice and information. Participants who discussed parents' anxieties – including young people, teachers, parents and non-parents – focused mainly on illicit drugs, though alcohol and nicotine use were also raised.

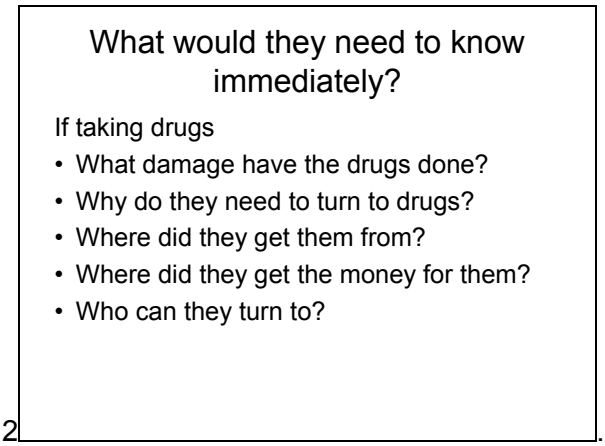
There was some discussion in the workshops about how attitudes towards parenting might influence attitudes towards the information that parents felt was acceptable for their own children and themselves. Some parents felt that they should keep information about drugs from their children to protect them, especially when they were younger, for example at primary school age. Their fear was that information might arouse curiosity and lead to experiments with drugs that might otherwise either have not happened or at least would have happened later in life. Information that acknowledges and addresses these fears may be of value.

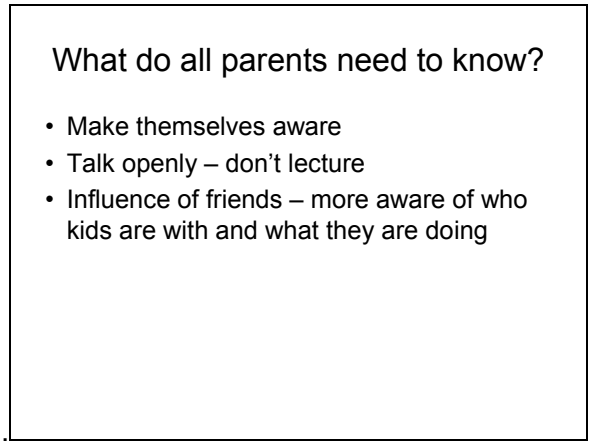
Others saw this view as misguided. They argued that if parents provided the information – which would mean they would have to inform themselves first – they could exercise more control over what their children knew, and help to foster an environment in which drugs could be discussed openly and honestly. Some felt that many parents were naïve about the current state of knowledge about drugs amongst young children in particular. In the Belfast workshop, a teacher spoke of some work that had been done in a local primary school. The children there had been asked to list all the words they knew that were used to refer to cannabis: they knew a lot. A first step in designing effective drugs education would be to acknowledge how much young children know about recreational drugs.

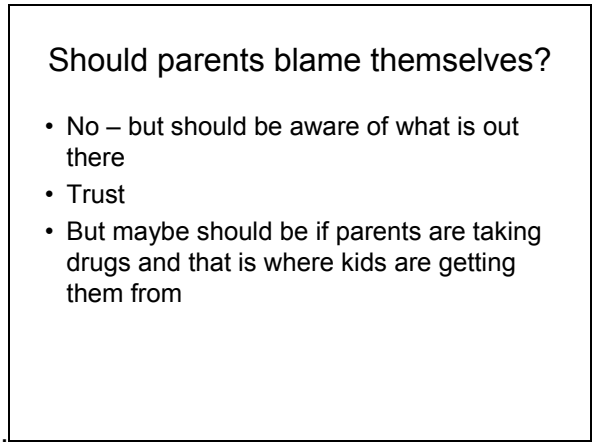
Participants in the Belfast workshop produced the presentation below. It looks at the information parents need to protect their children and to respond to a child discovered to be using drugs. Some of this information would need to come from the young person, including what had been taken, why, and where it had been acquired. Knowing who to turn to – they suggest drug awareness groups as one possible place – and what damage might have been done to the child are also important. Parents' attitudes are also covered in the presentation. They advocate not blaming yourself if your child is using drugs, talking to them openly and without lecturing, and learning about the world in which your child is growing up, becoming aware of 'what is out there.'

PRESENTATION BY PARTICIPANTS IN BELFAST WORKSHOP ON DRUGS INFORMATION FOR PARENTS

1. 

2. 

3. 

4. 

5.

What kind of support systems might be provided to parents

- Social Services
- More youth clubs for young people
- GP
- Drug awareness groups
- Internet

6.

What sources of information are trustworthy

- Not always doctors
- Internet

Vulnerable young people

As noted in the chapter on recreational drugs, participants discussed who uses drugs and why. Some argued that anyone could, that drug use is not confined to people from certain backgrounds and that recognising this was very important. It makes everyone responsible and may help to change some of the misconceptions and stereotypes about drug users. However, some features in a young person's background were thought by many participants to make them potentially more vulnerable to drug use, and to that use becoming problematic. These were outlined in the briefing notes provided to participants but many were identified spontaneously.

EXCERPT FROM BRIEFING NOTES ON DRUGS AND YOUNG PEOPLE

Risk factors:

- A young person's genetic make-up
- A young person whose mother used drugs whilst they were in the womb
- Individual characteristics such as an impulsive personality or doing poorly at school
- Family characteristics such as child abuse or neglect, or parents who have mental health problems or who use drugs
- Features of the wider environment such as the availability of drugs, peer pressure or the way drug use is presented in the media or films

Throughout discussions on vulnerability, there was tension between the benefits felt to follow from taking a more targeted approach and the disadvantages of labelling young people. Many participants were resistant to the idea of identifying specific young people as particularly vulnerable, because of what might follow from being labelled in this way and, as discussed in a later chapter, because those not seen as vulnerable may be ignored or seen as 'immune' to addiction.

A voting question was asked in the Belfast and Exeter workshops about whether social resources should be targeted universally or at young people whose family background or environment makes them more vulnerable to problem drug use. In both locations, more people favoured the universal over the targeted approach. In Belfast, 91% voted for the universal approach.[14]

> *'All children are vulnerable to drugs and addiction, whether genetically predisposed or not. Parents need to know their children, their friends and interests regardless.' (on-line participant)*

Peer pressure

Peer pressure was seen as playing the biggest role in young people's use of drugs. However, whilst all young people were likely to be subject to peer pressure, their levels of resilience were seen as varied. Low resilience was seen as making young people more vulnerable to peer pressure. Teachers in the Exeter group emphasised that this was a critical factor, influenced by the wider environmental and social features in a young person's background and the opportunities available to them in their social and educational life. Participants in the Exeter and Belfast workshops saw the use of drugs by parents as a particularly pertinent factor.

> *'Some students say their mum scores drugs for them.' (Belfast outreach – young people)*

In addition to honest education for young people about the possible risks and how to avoid them, many participants focused on the need to provide support for parents of young people who may be more vulnerable to drug use or abuse, additional to the general education and information that all parents would need. This might include parenting classes or mentors for families and young people. As with many other questions raised in the project, people returned to the need to address the issues around the drug use – including housing, education, social inequality and employment opportunities – in addition to the drug use itself.

> *'Those so identified might receive special, targeted prevention and education programmes which would explain the nature of the risk and the likely outcome should they start using. If they are identified on the basis of prior family history of addiction engaging the rest of the family in treatment services, where needed, would be important. General life skills education on dealing constructively with emotions, conflict and problem solving would also help. (on-line participant)*

> *'Maybe they should clean up areas like that, make it look better, start a youth forum.' (Belfast outreach – young people)*

If a young person had been identified as particularly vulnerable to addiction in the future, participants felt that monitoring was perhaps the most appropriate response. This meant

14 A third choice was provided in this question, which was 'vaccinating all babies to prevent addiction'. This received minimal support.

being aware of the risk and how serious it was and knowing about addiction in general. Knowing that support and resources were available was seen as vital. Some suggested helping young people to develop coping mechanisms to help them deal with frustration, anger and peer pressure.

Cognition enhancers

The question of young people's use of cognition enhancers was posed in two ways, as a treatment for attention hyperactivity deficit disorder (ADHD) and in the more general context of enhancing the cognition of 'normal' young people.

Cognition enhancers and ADHD

Parents of children and young people with ADHD were involved in the workshop and outreach groups in Glasgow. They felt caught between the debate over the use of Ritalin (methylphenidate) to treat the condition, the attitude amongst some that it is not a 'real' condition, their desire to do the best for their child and the general difficulties of coping with ADHD.[15] Some felt that things were changing, with more acceptance of ADHD. They drew comparisons with autism, which they saw as being more widely acknowledged. At least part of parents' anxiety about giving drugs to their children seems to be related to the uncertainty generated by this debate and the passion it arouses. It is also often accompanied by moral judgements on the choice made by parents about whether or not to give their child drugs.

Media coverage of ADHD and Ritalin seems to have contributed to the difficulty of the decision that parents of children with ADHD need to take. There is a stigma attached to the condition, with some participants suggesting people viewed it as 'naughtiness', without there being any underlying medical condition. If ADHD is viewed in this light, using drugs looks like a drastic solution. In the Belfast workshop, some participants suggested that the increase in use of Ritalin was linked to the way the benefits system worked. Parents were getting their child diagnosed and given drugs, they said, '*for the money'*.

Many of the parents of children with ADHD said they had tried other ways of helping their child, but in the end had decided drugs were the only solution, for a number of reasons. Some parents suggested that schools required it. They said that drugs were being used as a substitute for proper educational support and that if this were available, fewer children would be medicated. Some parents spoke of how effective the drugs had been. Some said that their doctor had turned to drugs only as a last resort. Others felt GPs were under-informed about ADHD.

> *'They are just classed as bad boys.'*
>
> *'Autism is well known and cared about, ADHD kids are on the same spectrum but no-one cares about them.'*

15 A majority of participants referred to Ritalin when talking about drugs used to treat ADHD. One or two mentioned methylphenidate.

'People think parents go straight for drugs but it is the last resort usually. Doctors are also reluctant to use drugs early on.'

'First of all parents must educate themselves then educate the doctor about what is happening to their child.'

'The choice is education with medication or no education at all – schools won't take unmedicated kids.'

'I wanted to treat my child without drugs to begin with but things got so bad that I had to go down the drugs route. My child was involved in the decision to use drugs, they only use them for school not home hours.' (All quotes from Glasgow outreach – parents group)

Parents' concerns over giving Ritalin to their children include the impact of the drug on their overall health, difficulty in finding the correct dosage, side-effects (primarily drowsiness), the consequences of taking one drug on their child's attitudes to drug use in general, and the impact of stopping use. Parents said this would happen when their child was aged 18.

'We need a better drug [than Ritalin] without the side effects.' (Glasgow workshop)

'Children with behavioural problems are increasing – there will be a lot more children who will be treated like zombies and will be dependent on drugs… Parents will be cornered into giving them the drugs.' (Merthyr Tydfil workshop)

Recreational drug use by young people with ADHD

Many parents of children with ADHD expressed concern that their offspring were more likely than their peers to use recreational drugs, for two reasons. The first is that. they would be accustomed to taking pills to adapt their mood and behaviour and may use recreational drugs to do this when they have stopped using methylphenidate. Parents worried about the impact of withdrawing medication – parents said this would happen when their child reached 18 years – if the symptoms were still present. Their concern was that the problems alleviated by the drug would return but be more difficult to cope with at that age than when their child was younger and that the solution, from the young person's perspective, might be to use illicit recreational drugs.

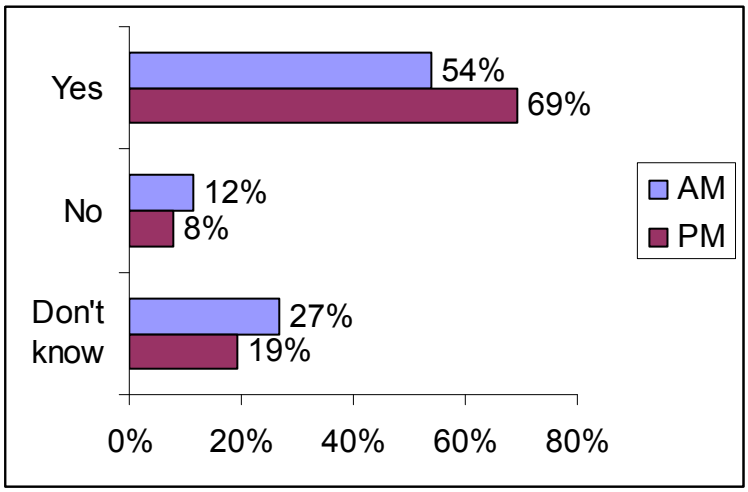
Second, their condition itself may mean they are less resilient in the face of peer pressure. Being seen as 'bad boys' by peers may mean they attract what parents see as the 'wrong type' of friends – that is, those who are already involved in drug use.

'It makes kids think drug use is normal, they don't see the difference between recreational and medicinal drugs. It is just self-medicating.' (Glasgow outreach – parents group)

'The lifestyle of ADHD kids is such that it leads to recreational drug use anyway. They start on the pharmaceuticals then go to harder drugs.' (Glasgow outreach – parents group)

The chart below shows the views of people in the Glasgow workshop, amongst who were parents of children and young people with ADHD, on the acceptability of young people using cognition enhancers to improve problem solving skills and concentration. When the question was asked, it was explained that this would include things such as Ritalin and that it was only about prescribed drugs. It has no statistical significance, but reflects the views of participants discussing this issue across all locations.

DO YOU THINK IT IS ACCEPTABLE FOR YOUNG PEOPLE WITH ADHD TO TAKE DRUGS TO IMPROVE PROBLEM SOLVING SKILLS AND CONCENTRATION?



Glasgow (n=26)

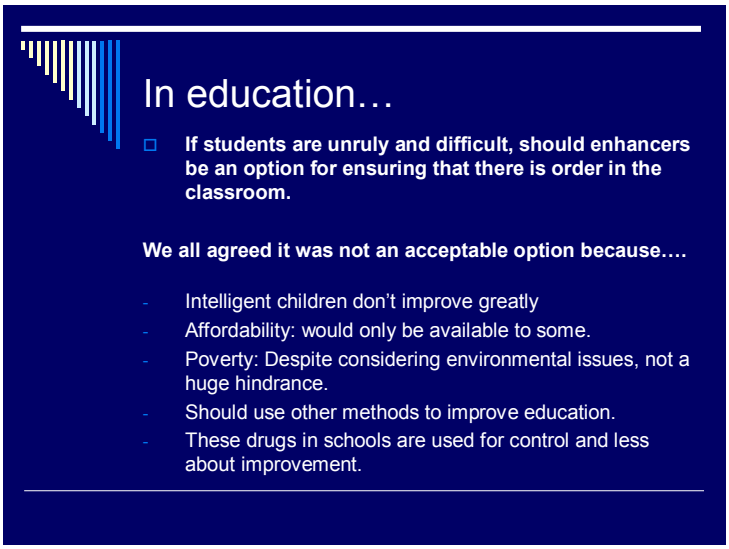
Cognition enhancers for all children and young people?

Participants were resistant to the idea of cognition enhancers being used by children and young people for reasons other than treating a medical condition. Much of the discussion focused on whether or not cognition enhancers would create a 'more level playing field' by helping less able children to catch up with their peers. Participants felt that if they were available for all children and young people to use, then this was unlikely to happen, unless their effect on the less able was greater than on their more capable peers. As with other participants' views on the use of drugs by young people, their impact on the developing brain was also a worry.

The main chapter on use of cognition enhancers by healthy people covers other reasons for participants' resistance to their use by healthy young people, including issues of equality and the intrinsic value of 'normal' learning.

The slide below, prepared by participants in the Glasgow workshop on cognition enhancers, illustrates some views on the use of cognition enhancers by children and young people in education. They raise the issue of the extent of enhancement and question whether it would be particularly marked anyway. Affordability, concerns over control and the importance of improving education in other ways are given as reasons for rejecting the use of these drugs in education.

SLIDE PREPARED BY PARTICIPANTS IN THE GLASGOW WORKSHOP ON COGNITION ENHANCERS



'I am worried that you have to take them just to keep up with everybody else and therefore my choices will be smaller, if everybody in the class is taking them then I would have to think about giving them to my children.' (Glasgow workshop)

'I've got young children. Will they be saying to me, 'Can I take this drug because everyone else is''? (BB2)

'I don't think children & young people should be allowed to use cognition enhancers, because it would give an unfair advantage to the richer families who could afford to pay for them. Unfortunately due to the way our society is run they will be available to the young, and the poor will probably have to steal to gain their share. Which opens another problem which isn't there now so a lot of thought will have to be given on how these are distributed fairly.' (on-line participant)

Some on-line participants argued that young people should have the same rights as adults to use cognition enhancers, providing they were safe and without side effects. Only a very small minority of face-to-face participants supported this argument.

'As long as they are thoroughly researched and approved as safe to be administered in the home, without serious adverse consequences in the long term, that decision should be left with the parents and child. If a particular substance can safely help with examination nerves, memory, concentration, confidence etc, then why not use it to boost your child's chances in a competitive society. If cognition enhancers can be developed that help with behavioural/social problems in children, then let's hand them out.' (on-line participant)

'[W]e are in a world of globalisation and if this is what it takes for our children to compete then so be it.' (BB2-IL)

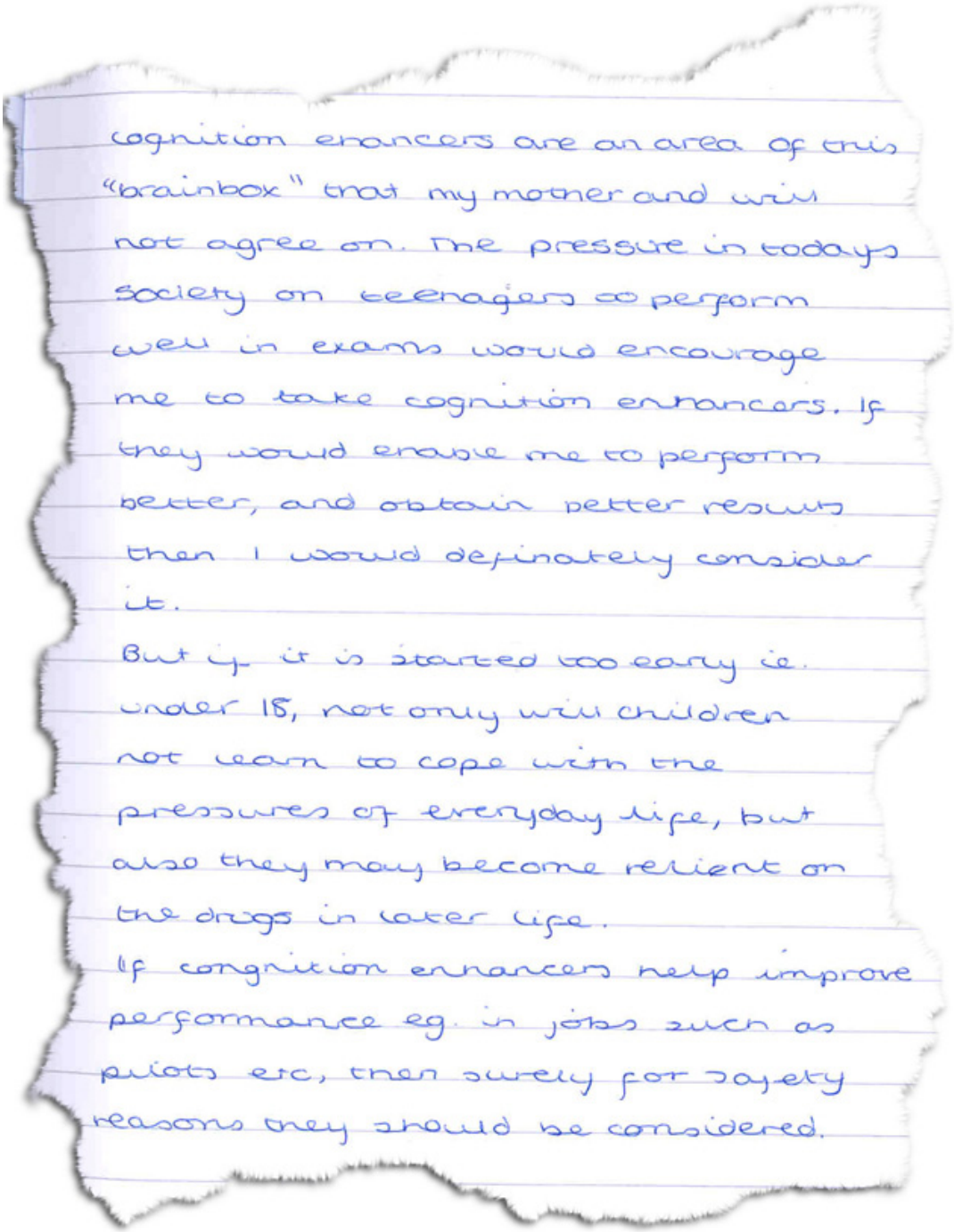
Finally, the diary kept by a young carer who accompanied her mother to Brainbox (see below) illustrates a view that was not heard in the face-to-face work

Conclusion

Much of the discussion of young people's use of illicit recreational drugs was focused on education and prevention. Participants thought that a more balanced approach to education would increase its effectiveness. At the moment, young people are told of the harms of drug use but see none of these harms affecting those around them who are using drugs. So they are unlikely to be persuaded by the information. Involving people in the design and delivery of education who have used drugs, and providing education at an earlier age, are also seen as important. Taking drugs education out of school and including information on alcohol are also suggested. Participants' concern about the use by young people of illicit and licit recreational drugs cannot be over-emphasised.

Cognition enhancers are seen as valuable in helping young people to cope with ADHD, but the continuing debate about the condition itself – is it real or are these young people just 'naughty'? – and the use of Ritalin to treat it muddy views somewhat. Parents of children with ADHD are caught in the middle of this debate. One of their greatest concerns was the impact on their child of growing accustomed to using drugs to control mood, and whether this heightens their risk of using recreational drugs. Only one or two participants thought that healthy young people should be given the same choices as adults about using cognition enhancers.

EXTRACT FROM DIARY KEPT BY YOUNG CARER ATTENDING BRAINBOX.



cognition enhancers are an area of this "brainbox" that my mother and will not agree on. The pressure in todays society on teenagers to perform well in exams would encourage me to take cognition enhancers. If they would enable me to perform better, and obtain better results then I would definately consider it.

But if it is started too early ie. under 18, not only will children not learn to cope with the pressures of everyday life, but also they may become relient on the drugs in later life.

If congnition enhancers help improve performance eg. in jobs such as pilots etc, then surely for safety reasons they should be considered.

9. Control and regulation

Introduction

If the future is a world in which no one takes recreational drugs, the difference between that future and our present will be most evident in creative and cultural achievements. In looking at the question of whether adults' rights to take drugs should be limited and what would be gained or lost if no one took recreational drugs in the future, participants focused primarily on the impact on art, music and literature. Another thing that would be lost, they felt, was the possibility of escapism. More practically, and looking at licit and illicit drugs, the economy would suffer as the face of leisure industries changed, brewers and distillers went out of business and people stopped profiting from the trade in illicit drugs. Jobs would be lost in the health service too.

There would be gains in a drug-free society too. The amount of money needed to fund police anti-drug activities, prisons and the health services would plummet. Families would benefit too, as the anti-social aspects of drug use disappeared.

As we have said earlier in this report, however, participants do not think drug use is preventable – and some do not see it as desirable. Instead, they focus on what the limits of use should be and on the education that will help to prevent as many people as possible from taking drugs. In this chapter, we look first at participants' views on where those limits should lie and to which substances they should apply. We look next at attitudes towards health-based approaches and law-based approaches to drug use. Finally, understanding of and attitudes towards drug classification are explored, including the views specific to some of the people using drugs who were involved in the work.

Limits to drug use[16]

Around half of the on-line participants looking at the question of what limits should be placed on the right to use 'recreational' drugs said there should be none, if use had no impact on those around the user. However, since they saw this as seen as unlikely, limits needed to be imposed to minimise harm. Some limited their understanding of harm to immediate risks to the user and others, such as accidents or injury resulting from intoxication, but more included the wider harms to the user's family, drug-related crime, violence, and social problems resulting from family disruption and the economic cost of treating drug users.

> *'Provided such drug use has no impact on anyone else, they should be free to try what they like. However, the reality is very different. Drug use inevitably has an impact on a user's health, relationship with their family, ability to cope at work etc.*

[16] The term 'drug use' in this chapter refers to use of those drugs which are currently illicit. It does not include licit recreational drugs such as alcohol and nicotine. There was no support for bringing these within the same regulatory framework as illicit 'recreational' drugs.

> *Many people feel that they can enjoy the odd sniff of cocaine in a controlled environment and continue to lead a very normal life. It is true that this can have little or no impact on anyone else and cause no harm. But there are many people whose lives, and the lives of people around them, are completely ruined by drug addiction. These people need protection from themselves especially if they are carrying an addictive gene. The only way to do this is by controlling the availability of drugs through legislation and educating people of the dangers.' (on-line participant)*

Other on-line participants said there should be no limits and did not qualify this with a reference to harms. They emphasised individual choice and responsibility and several argued that this should go hand in hand with sufficient education so that people understand the risks they are taking. Some respondents felt that removing the existing limits to people's enjoyment of currently illicit recreational drugs by legalising their use would lower the cost of drugs, remove dealers and therefore reduce drug related crime and its consequences.

> *'No limits should be placed. Rather than living in a nanny-state (which we increasingly are it seems), people should be left to decide what they want. If a person decides to take cocaine, and they are informed of the risks, then it is their decision to make. People should still be educated about the serious dangers of drugs, but ultimately it is their decision whether they want to involve themselves in them or not.' (on-line participant)*

> *'We should just raise awareness – people are capable of making decisions themselves. If you know the risks and you take them anyway - you should have a choice.' (BB2)*

Amongst all participants who discussed this issue, agreeing an age at which drug use might be allowed was difficult and, in the end, no agreement was reached. Suggestions ranged from over-16s, over-18s to over-21 year olds. The primary reason for instituting an age-limit was to protect developing brains, as noted in the chapter on young people. Whilst some respondents believed that other than age restrictions, drugs should be legal and available to use by competent adults, and some refined this by limiting legal use to 'softer' drugs such as cannabis, a majority were not in favour of ending prohibition.

Some participants suggested a controlled market, with access restricted to small amounts or use for a limited time. Some of those who argued for adults' rights to use drugs for enjoyment specified that this should not be actively promoted or used for commercial gain. A small number of people felt that drugs of any kind should only be allowed on prescription, and for medical rather than enjoyment purposes.

> *'I know I am probably rather old-fashioned, but I do feel society would be a better place all round if drugs were not used for any of these purposes.' (On-line participant)*

In the face-to-face work, no participants felt that it was realistic to think that drug use could be eradicated. A majority of people, after a reminder that recreational drugs include alcohol

and nicotine, felt that it would perhaps not be desirable either. Their focus was on educating young people as effectively as possible about the potential dangers of recreational drugs; ensuring that those who do use drugs do so as safely as possible and that drug addicts, including alcoholics, have access to the services necessary to help them through withdrawal and the support they need to put their lives back together.

What would legalising drugs mean?

The harms arising from recreational drug use were thought by many participants to result from their illicit status, the penalties attaching to use, the absence of good support services at an early stage for people who are beginning to experience problems and inadequate health services. They point to the number of people in the UK who use illicit drugs at one period in their life and then continue use of recreational drugs by switching to alcohol in later life. There are differences, however, in participants' views on how to address these various factors seen as implicated in the overall harms. Many people argued that currently illicit recreational drugs should remain classified and focused on how to improve the social and health support provided to people who continue to use and on how to make use as safe as possible. Some bolstered this argument by pointing out that alcohol and nicotine have been legally available for many years and are now recognised as being amongst the most harmful of all recreational drugs, with alcohol in particular having clear economic and social costs and rising use by young people. Attitudes towards our current approach to drug classification and on the policy area under which drug use should fall are addressed in later sections. First, we look at some views on the possible consequences of bringing drug distribution into the legal economy.

This was discussed in some detail in the Exeter workshop. Some participants focused on the positives of legalising the recreational drug market, arguing that quality could be assured and it would be possible to gain more accurate information about the extent of drug use. They felt too that crime associated with use of illicit recreational drugs would decrease, as would the harms, since people would be less circumspect about seeking help and more likely to seek it at an earlier stage. This was seen as helping to prevent chaotic use, job losses and family breakdowns that can be associated with problem use of illicit recreational drugs. Whilst the number of users might increase, it was seen as less likely to become problematic because it would no longer be hidden and would be compatible with living a stable life. As noted earlier, some on-line participants also held this view.

Those who felt the effects of a legal recreational drugs market would be more negative argued that the incidence of drug use would increase and that, even if legally available, people would still need money to buy them and hence still commit crimes to get that money. With more people using drugs, they felt that the overall reduction in drug-related might in the end be minimal. More users might also, they felt, lead to an increase in mental health problems associated with drug use. Some suggested that it could impact on obesity, with more cannabis users getting the munchies.

Some thought was given to the kinds of regulation that would be required if currently illicit recreational drugs (in particular cannabis) were legalised. Monitoring sales was seen as important, with good stock control processes to ensure that staff kept to any regulations on sales. Some participants were concerned about vulnerability of those who worked in legal

drug outlets and the potential for robbery from the premises where drugs were legally available.

Restricting access was also discussed. Whilst participants agreed that there would be a need to limit the amount that people could buy and on the strength available, they debated the appropriate age limit and none was agreed. They saw some limit as necessary, but also felt that young people would probably start taking drugs anyway and that providing a legal supply would ensure that information about use was available and they were kept from involvement in the illegal market, where quality would be less certain. Consideration would also need to be given to pricing. Some participants felt that commercially available drugs were priced too highly, the legal supply might be undercut by the black market, as is happening at the moment with cigarettes.

Having designated areas for drug taking was a further suggestion, with Amsterdam coffee shops given as an example, was also seen as necessary restriction on legal cannabis use. Some participants suggested a 'drug-using theory test' that people would have to do before being allowed to buy drugs, using the driving theory test as an example. They stipulated too that no advertising would be allowed. Discussing price, they felt that this should not be too high, so that people did not return to the black market.

> *'I don't think prohibition is working. Recreational drugs seem to be in the hands of criminals and drug barons. If you could buy recreational drugs over the counter of Boots at least you'd know what you were buying.' (BB2)*

Drug classification

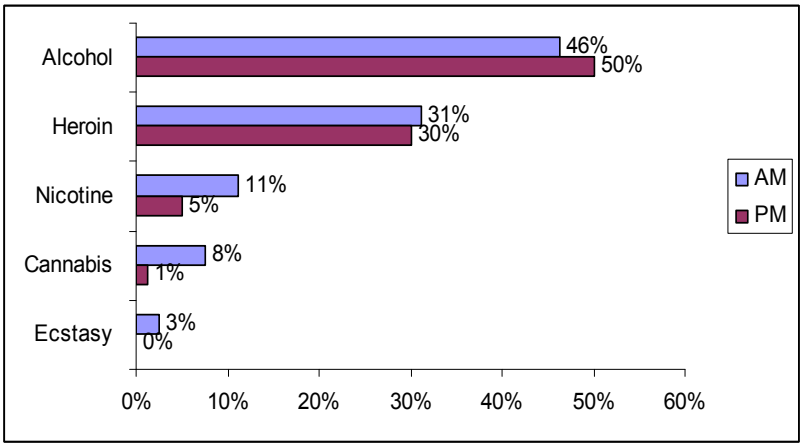
The overall view of a majority of participants was that the current drug classification system is confused, inconsistent and arbitrary. Whilst the specific rationale behind the system was not explored in any detail, initial discussions showed that most participants thought that it had been developed on the basis of the harms associated with particular drugs. However, following further discussion and consideration of the harms arising from use of 'recreational' drugs, including alcohol and nicotine, the underlying rationale became increasingly unclear. The reclassification of cannabis and more recent coverage in the media about 'skunk' furthered the confusion.

> *'The drug classification system is a mess isn't it? It's a complete mess.' (BB2)*

> *'Because [drugs are] illegal it therefore causes deprivation and it is difficult to separate the two things.' (Belfast workshop)*

The chart below shows the views of participants from Belfast and Liverpool on the harms to wider society of different drugs. It shows that the harms attached to alcohol use are viewed as more serious than those attached to any other drug listed. Whilst this data has no statistical value, it does accord with the views of participants in other locations who discussed this issue.

WHICH OF THE FOLLOWING DRUGS DO YOU THINK CAUSES THE MOST HARM TO WIDER SOCIETY?



Liverpool, Belfast (n=80 AM, 72 PM)[17]

Some of the confusion was clearly traceable to the reclassification of cannabis as a Class C drug and the more recent media stories claiming drastic increases in the potency of the drug. Uncertainty about the media coverage of drugs, highlighted in discussions of celebrity cocaine use, together with what appear to be confused messages from government, make it very difficult for people to reach a firm conclusion about how individual drugs should be classified. However, a general message emerged about the approach that should be taken. A majority of participants felt that the drug classification system should be revised to reflect accurately the harms associated with each drug and that this should be changed only on the basis of new information that invalidates the existing weighting of harms. There was no discussion of how frequently classification should be reviewed but it was clear that if a review was to take place, the reasons for it should be made explicit.

Public health or criminal justice?

Many participants who discussed future drug use and our approach to drug users felt competing impulses, expressed succinctly by a participant from Liverpool.

> *'I know in my head that rehabilitation is better, but if it was my house that had been burgled, in my heart that wouldn't be enough punishment'. (Liverpool workshop)*

For a majority, the primary concern for the future was to reduce the personal cost of drug use. This would mean bringing problematic recreational drug use within a framework of public health and harm reduction. There would be a more open approach to drug use and drug users, including effective education, safe environments for consumption, quality control, and widely available and accessible health and support services for all drug users who wanted them.[18] Any crime committed by a drug user would be dealt with in the same

17 The drop in base numbers between the morning and afternoon voting is due to the younger participants (under 16) leaving at lunchtime.

18 As noted earlier, few participants used the term 'harm reduction', though they referred to services and support that would fall under this term.

way as the same crime committed by a non-drug user. The punishment for large-scale dealers and traffickers would be long prison sentences and sequestration of assets.

The majority of participants did not see sending people to prison for possession and use of illicit recreational drugs as effective. Prison was seen as likely to exacerbate rather than curtail drug use. Drugs were seen as being easily available inside prison, and drugs services very limited. The experience of prison, for women in particular, was regarded as being more likely to add to the factors that may have led to problem drug use in the first place than to reduce them. Some of the users involved suggested they had learned more in prison about how to take drugs and what could be used as a drug than they would have in the outside world. Very few participants were hard-line in their approach, arguing in favour of prison. Even amongst those who held this view, some saw the issue in terms of harm to others, rather than law-breaking.

> *'The police are not hostile – they're major allies in recognising that prison is not an answer.' (London outreach – users group)*
>
> *'Putting people in prison is asinine – it's counter-productive.' (London outreach – users group)*
>
> *'People should be free to choose their own lifestyle until they affect the lives of other people – then lock them up and throw away the key.' (BB2-IL)*
>
> *'There is a difference between government policy, with the Home office and the Department of Health. The latter will focus on harm reduction, the former on the criminal element. The question is who will take control? (Exeter outreach – user/ex-user group)*

The following table summarises the individual views of participants in Brainbox 2 on the relative benefits and disadvantages of a criminal justice and health-based approach to illicit drug use, as expressed in their Information Logs. Most entries are verbatim. Changes have been made only to group similar suggestions into a single entry.

Sending people to prison for using illicit recreational drugs	
Benefits	*Disadvantages*
Reduces drug-related crime Removes users from society Will make people think again about committing the crime of taking a banned recreational drug. None No benefit. May keep Alleviates the problem Secure environment in which to give support	Links to people who will encourage drug use and other criminal acts. Does not work Does not solve the problem. Expensive None Normally sentences are too short. They go back to use/associated crimes such as prostitution/street crime once released Drugs too freely available in prisons. Prisons are already full and need space for murderers etc. Short-term solution. Overcrowding for not very serious crimes. Costs to society of housing people in prison.

Providing health and other treatment to reduce the harm of using recreational drugs or help to overcome addiction	
Benefits	*Disadvantages*
Reducing addiction would reduce cost in terms of care and support. Reduction of drug-related illnesses Right way to go. Keep one area where the drugs users can stay clean Users are more likely to succeed in staying off drugs safely. Prevention of spread of diseases This will benefit with counselling before drug treatment. Quality of life. It gives support to users to come off. Re-introduces person to society. Fewer burdens on society. Reducing addiction will reduce costs in terms of care and support. Reducing the spread of disease.	Cost to society Needs funding or system will fall apart Encourage others to start taking drugs. Teenagers might see it as a new hobby to do, place to go Not everyone wants help. That the users become dependant on services without full withdrawal Costly Pampering to the weak Encourages the use of recreational drugs

'I had clearance from the Governor to talk about drugs, but the guards wouldn't let me.' (Liverpool outreach – user/ex-users)

The view that a public health approach to drug use was more effective than criminal sanctions was also shared by many participants in the on-line work, with the proviso that any crimes committed would be treated in the same way, whether or not drugs were involved.

'There is little point in punishing addicts. Sending them to prison may even put them in a position where drugs are more available, and it won't help rehabilitate him. Addicts should be treated and helped back into society where they can contribute, rather than being punished and be a drain on the taxpayer.' (on-line participant)

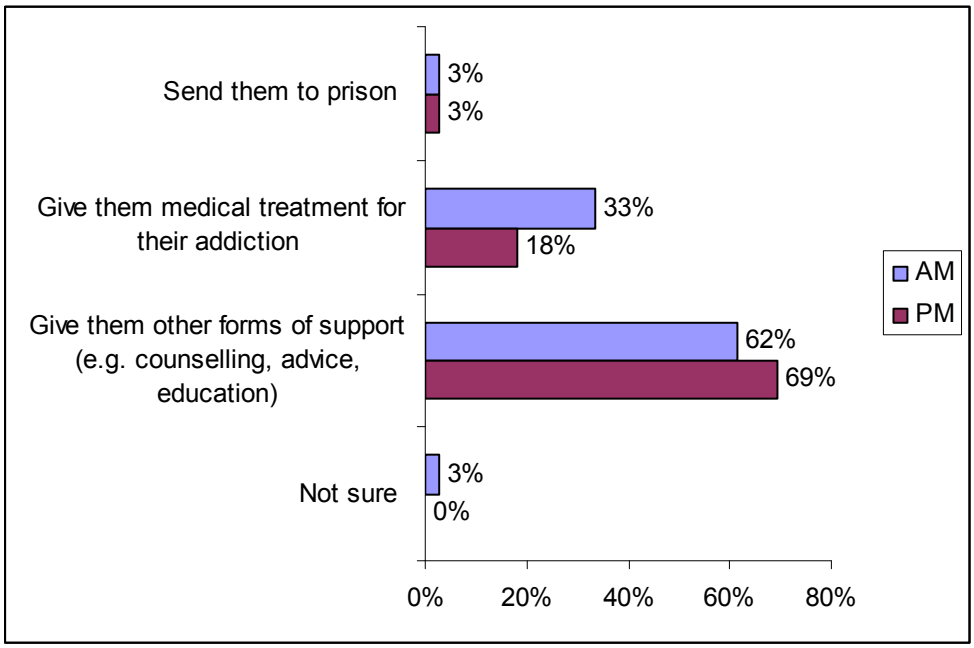
'Prison doesn't help users, and is more likely to start or make habits worse than being outside.' (Norwich outreach – discussion group)

A small number of participants felt that criminal offences, including possession of illicit drugs, should be punished and that addiction should not be a sufficient excuse for crimes. They suggested that repeat offenders should be seen as having made a choice to be criminals and not treated medically.

Several participants in the on-line work felt that neither approach was appropriate as drugs should be legalised. People should be treated as individual human beings and accept personal responsibility for the effects of drug taking. Some people challenge the term 'ill' for drug addicts – they acknowledged that help was needed but felt that this need not be medical help. Those few users whose drugs of choice were not addictive saw the focus on health as problematic, arguing that this in itself positions use within a particular framework that is not applicable to a great majority of users.

The chart below has no statistical value but is indicative of the views expressed by a majority of participants in all groups discussing illicit drugs.

WHAT DO YOU THINK IS THE BEST COURSE OF ACTION FOR SOMEONE WHO USES ILLEGAL DRUGS?



Liverpool (n=39)

Would harsher punishments be effective?

As noted above, a majority of participants in both the face-to-face and on-line work did not think a criminal justice approach to illicit recreational drug use was effective, and thus a majority saw little point in introducing harsher punishments. It was important, however, to explore the alternative of taking a more hard-line approach, with longer prison sentences for illicit recreational drug use. This met with very little support. Since people use drugs despite their illicit status, harsher punishments were seen as making little difference or as having a negative effect on users and on society in general. On-line participants identified a number of potential negative effects, including making users more desperate or careful to avoid capture, driving up prices and therefore increasing the number of drug-related crimes, increasing the number of people in jail, and increasing drug use overall.

> *'It may deter a few from starting in the first place but those who are addicted would use anyway. Using despite adverse consequences is one of the diagnostic criteria for addiction.' (on-line participant)*

> *'I think harsher legal punishments would deter people who use illegal drugs casually but would have no effect on people who are addicted. It may even deter addicts from seeking help to overcome their addiction.' (on-line participant)*

> *'It will further impoverish them, it will further discriminate against them, it will further exclude them. It will have effects on the whole of society. It will make society less fair, less inclusive and less sustainable. It will increase crime, and increase the levels of violence criminals will use to protect themselves. In turn, this will increase the levels of violence the state uses to combat criminals.' (on-line participant)*

'The only effect that harsher punishments will definitely not have is to reduce the amount of drug taking in Society. The opposite will occur...Riskier drug taking will replace less risky, and the overall harm caused will increase.' (on-line participant)

Users' views on control and regulation

The presentation given at Brainbox 2 by Keri Tozer and Sue Garnett from The Relay Project echoes many of the views expressed by other users who took part in this project. Those who argued for an end to prohibition and used illicit recreational drugs without experiencing problems might not agree with some of the points made. However, the knowledge and experience of problematic drug use by those who developed this presentation gives them a more informed perspective than the majority of participants recruited as 'general public' and their views on control and regulation warrant separate attention. They looked at four drugs: alcohol, cannabis, cocaine and heroin.

Alcohol

The social acceptability of alcohol use should not detract attention from its harms, to both physical and mental health and resulting from both long-term use and binge drinking. The Relay Project argued for increasing restrictions on the sale of alcohol, both by changing opening hours, raising the age limit from 18 to 21 and training licensed managers and staff on the responsible sale of alcohol. Improving the security and reliability of identification required before being allowed to buy alcohol was also recommended. Finally, working with the children and families of drinkers to prevent learned behaviour was also seen as important.

Cannabis

The Relay project argued for the re-classification of 'super-cannabis,' or skunk, to Class A. They called too for more studies on the effects of cannabis use on mental health, with a focus on young people and people with a family history of schizophrenia, substance misuse or depression. Looking at the effects on short-term memory was seen as particularly important.

Cocaine

The view of general public participants that the media glamourised cocaine use was repeated by some of the participants who used illicit drugs. They did not advocate attempting to control this publicity, but instead advocated countering it with effective education. This would include highlighting some of the dangers of cocaine, especially used over the longer term. These dangers were identified as aggression, depression, addiction and neglect of health. Education should include the dangers of contracting blood-borne viruses from sharing snorting equipment, and information on the financial implications of cocaine use. Cocaine was seen as one of the most expensive drugs and particularly popular with young people who can least afford it.

The need for more investment in producing a naltraxone-type blocker and better treatment options for cocaine users were also mentioned.

Heroin

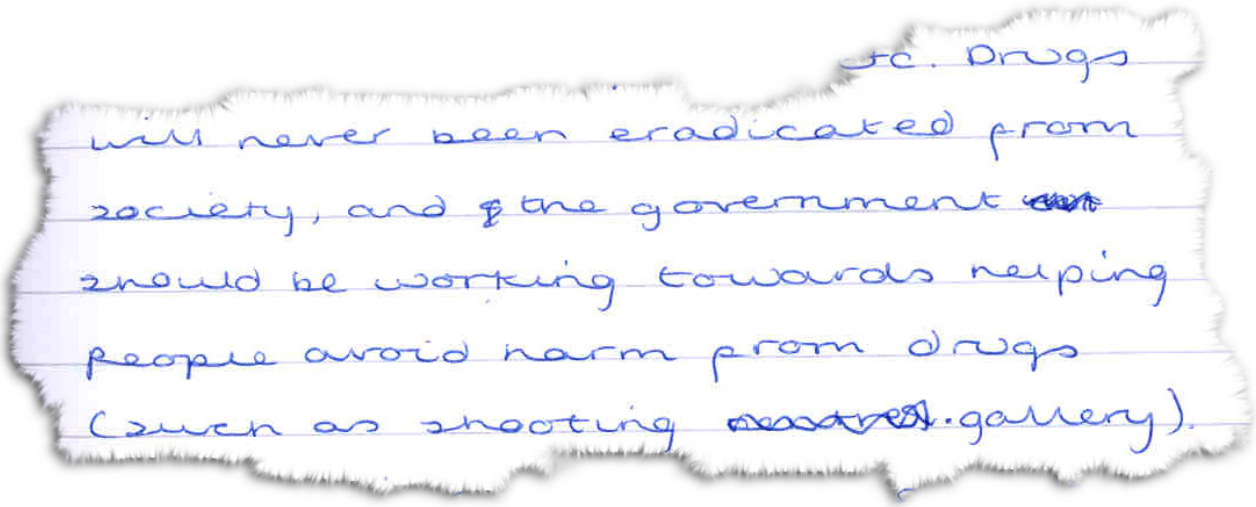
Heroin trafficking, along with cocaine and crack cocaine trafficking, was seen as the 'greatest single threat to the UK in terms of the scale of serious organised criminal involvement, the illegal proceeds secured and the overall harm caused'. The Relay Project presentation referred to a Home Office estimate of the costs of the harm caused by Class A drugs, citing a figure of £1.3 billion. This covered profits from sales, crimes committed by addicts to fund their habit and the damage to addicts' health, family life and wider community.

They recommended that pharmaceutical-grade heroin should be prescribed to users, a recommendation also made by other heroin users and ex-users taking part in the project. The consequences would be to:

- Reduce the need to commit crime to fund addiction
- Reduce the cost of policing the importation of illegal drugs
- Reduce the harm associated with poor quality heroin, high levels of cutting agents, talcum power, rate poison, brick dust
- Reduce the cost to health services.

(These bullet points are taken verbatim from the presentation.)

NOTE FROM DIARY KEPT BY A YOUNG CARER ATTENDING BRAINBOX 2.



Conclusion

There was general agreement that some drugs – those that we are calling here 'recreational' – need to be controlled more strictly than others – such as coffee or tea, for example. How that control should work was debated. A very few felt that ending prohibition was the most sensible and effective solution. Even then some form of regulation would need to remain, in the form of licensed outlets, restrictions on quantity, or age limits for purchasing and using. A majority thought that a classification system based on a thorough assessment of the relative harms of individual drugs was needed. There was some discussion of whether 'ordinary' cannabis (ie, not skunk) should be included within it.

An approach to users based on public health and harm reduction was seen as more effective than locking them up. It would mean more resources dedicated to providing the support and help needed by addicts, and to ensure that general practitioners and other health providers were as knowledgeable about addiction and drug use as they were about other problems with which their patients might present. Providing safe environments for drug use, such as user galleries, and ensuring that users are aware of the wider health implications of their drug use, were also seen as important. It was thought that this approach would be resource-intensive initially but would be more economically efficient over the longer term.

10. Cross-cutting themes

Introduction

The five workshops were structured around themes, rather than the three classes of drugs discussed in previous chapters. Some of the issues explored do not fit neatly within those chapters, cutting across the themes and classes of drug. In this chapter, we focus on these cross-cutting issues. These include identifying vulnerability to drug use becoming problematic, either genetically or by looking at social and environmental factors, attitudes towards genetic testing, and 'anti-addiction' drugs.

Identifying vulnerability

Participants were asked what they thought the differences were between being identified as having a genetic vulnerability to addiction and being told that your environment makes you more likely to become a drug user. Attitudes were affected by the general concerns expressed about the implications of genetic testing, which are covered in the next section. Overall, people felt there would be more value in understanding drug use within a social context, since more options were available for addressing this, whether through social policy or by individuals removing themselves from that environment. This second option would, of course, be more difficult for younger people. Some suggested that the identification of vulnerability on the basis of genetics would situate the problem at an individual or family level, where the government either could not or should not intervene. Vulnerability identified on the basis of social or environmental factors was seen as an issue for the government to address.

Some of the on-line participants felt that it was not possible to differentiate between the two methods of identifying vulnerability since too many questions were left unanswered. The availability of information about the implications of each method of identification was seen as important. For example, would health or social services respond to a genetic identification of drug vulnerability in the same way as to an identification on the basis of social or environmental factors? Would the same support, services or information be offered? Would the same level of resources be available? The age of the person being tested could also affect attitudes. For example, young children are likely to be less able to make an informed choice than young people in their teens.

> *'Being told you have a genetic predisposition could be interpreted as 'you can't help it', so removing the sense of personal responsibility for your actions. It could also limit a person's belief in their own self-efficacy to change the future, and lead to self-fulfilled prophecy situations. 'Environmental factors' gives a person choices about what they do, and links behaviour to outcome. A genetic test allows the prospect of punishing people before they have engaged in problematic drug use, by being used as an assessment tool for law enforcement.' (on-line participant)*

Genetic testing

Participants discussed the possibility of developing tests for genetic predisposition to addiction and to mental health problems, and the value that might lie in such tests. Many of the questions raised were pertinent to both addiction and mental health and related to the specifics of the test and the knowledge generated as a result of taking it. Underlying the discussion was a question about the relative balance between the contribution of genetic factors on the one hand and environmental factors on the other. Participants expressed this in terms of 'nature versus nurture'.

How would the test work?

One set of concerns relates to the test itself. Participants wanted to know how intrusive it would be – for example, would it be as straightforward as a blood test? On the assumption that it would be, they asked then how accurate it was likely to be. Would it identify the specific substance to which an individual was predisposed to become addicted? Would it identify susceptibility to a particular mental illness? If it showed that a particular person had a higher than average likelihood of developing a specific mental health problem or becoming addicted to heroin, for example, would it be possible to quantify the probability? And how accurate was the test likely to be? Many felt that their responses would differ depending on the answers to these questions. If a test was very accurate and it showed that the probability of an individual developing problems in the future was very high in comparison to the average population, some were more positive about the idea of testing.

The impact of the test on individuals

A further set of issues relate to the individual taking the test and their immediate family. Participants considered the consequences for a person undergoing such a test and the impact it might have on their own behaviour and that of people around them. They were concerned that testing 'positive' (ie, higher than average probability of developing a mental health problem or an addiction at some future point) would result a kind of fatalism: 'I'm going to be an addict anyway so I might as well start now' or 'I'm going to have a mental illness, this thought/action/fear must be the early sign'. The line between identifying a problem and providing positive help and support, and labelling the person with that problem in a negative way was seen as very fine. Alternatively, testing negative might mean that people think they are safe from addiction or mental illness and are free to disregard the potential consequences of using drugs or neglecting their mental health.

In discussing whether there would be value in such tests being given to young children, participants argued along similar lines, focusing on the behaviour of the parent rather than that of the child receiving the test. If a child was tested 'positive' for addiction or mental health problems, parents might become over-protective or if test results were 'negative', may be blasé and less likely to seek out information on drugs or mental health.

> *'Would the parents be more protective?' (Exeter)*

Wider social implications

A final set of worries relate to the impact of genetic testing on wider social attitudes to both addiction and mental health. This seemed to be the strongest determinant of the final position taken by participants towards genetic testing. All who discussed the issue raised these concerns. It links also to a further theme that ran through discussions on the future, which is the concern that we are gradually eliminating weirdness in society, as what counts as 'normal' becomes ever more narrowly defined. In several groups looking at this issue, people made spontaneous and independent reference to the film *Gattaca*, in which people's fates are determined directly by their genetic makeup.

Participants felt that if a genetic basis for addiction or certain mental health problems were sufficiently well founded for a test to be developed, and individuals took that test, we would come to look at both states as forms of disability. This was of special concern in relation to more severe mental health problems such as schizophrenia. Once such conditions were seen as disabilities, the next question would be whether parents might start to ask for the test to be done on their unborn child. And from there, participants felt the next step could be that aborting foetuses testing 'positive' would come to be seen as acceptable or even required.

> *'Would people terminate their children if they were found to have this disposition?' (Exeter workshop)*

> *'There will be more things defined as an illness… they will narrow down what is acceptable as a human being. Therefore they will define what is normal and everyone will have to be a normal person, like a sci-fi.' (Glasgow – student outreach)*

Testing for mental health problems

Benefits

Participants were more positive about a test for identifying susceptibility to mental illness than they were about a test for identifying susceptibility to addiction. Such a test might allow action to be taken on the basis of knowledge, including learning about mental health and providing the young person with coping strategies. Many of the issues raised are captured in these two slides, taken from a presentation prepared by participants in the Belfast workshop. Arguments in favour of testing included early warning allowing preventive steps to be taken, and economic benefits as people remained in work and were less likely to call on health services. They also raised, but questioned, the possibility that knowing mental health problems had a real physical basis would help to reduce the stigma of suffering from one. Participants felt that at present, mental illness is still at times equated with moral weakness. Providing a genetic explanation was seen as a way of breaking this equation.

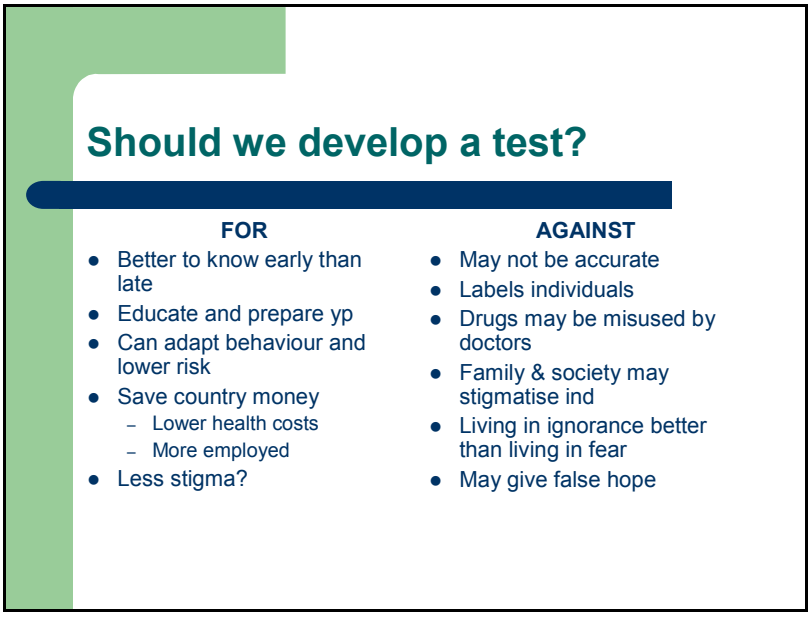
Disadvantages

Arguments against testing include the fear of labelling and an increase in stigma. This concern was linked to that of a narrowing definition of 'normality'. Participants suggested too that living in ignorance might be better than living in fear, especially if the support or

information necessary to help someone understand and cope with the meaning of the results were not available. They suggested too that the availability of tests might create hope of a cure that might not be forthcoming. In the context of testing young people, the possibility of risk-taking behaviour in the case of people testing 'negative' was suggested.

The group that developed the slide below looked at some of the arguments for and against developing a test for identifying genetic susceptibility to mental health problems. In addition to the issues discussed above, they raised the question of how the medical profession might respond to an individual testing 'positive'. They were concerned that doctors might be over-keen to use drugs as a way of preventing the development of mental illness in people testing 'positive'. This worry sits within the wider context of participants' views about the ease with which they feel drugs are prescribed, when other measures might be more effective and less debilitating.

SLIDE TAKEN FROM PRESENTATION DEVELOPED BY PARTICIPANTS IN BELFAST WORKSHOP



'Unsure as to ethics of the idea. Why not do a blood test for other things e.g. homosexuality? I think it's ethically wrong. Blood test for being stupid?'

'It could be 20 years before mental health problems come out so you would have 20 years of worry.'

'Information may be detrimental i.e. to career'

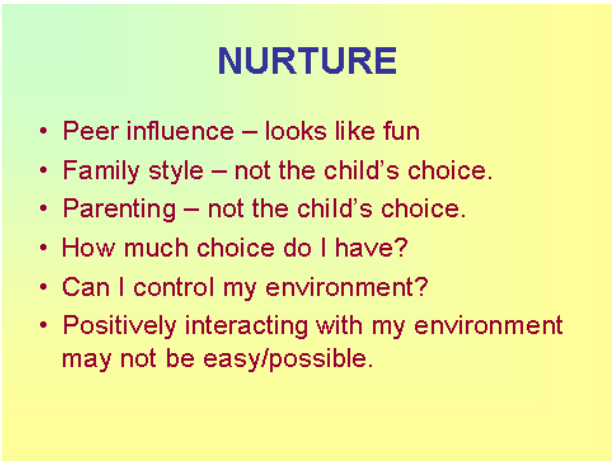
'May be a possibility of the illness being treated for it when they do not actually develop it.'

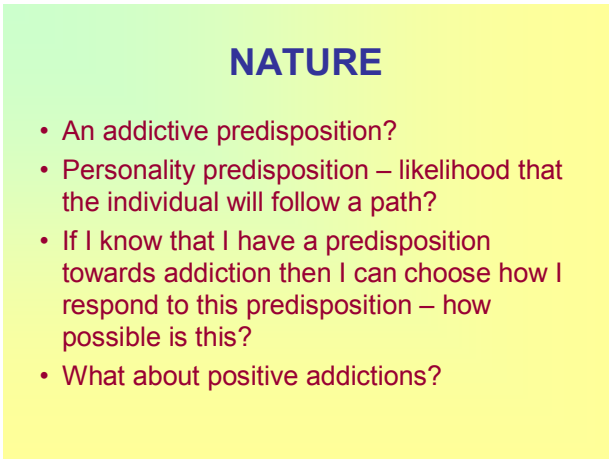
'You would know what symptoms to look out for and find out the history of illness and how it would impact on the child.'

'Very good idea as the awareness will be advantageous to treat it early.' (All quotes from BB2) [19]

Testing for addiction

The following two slides, produced by participants in the Exeter workshop, illustrate some of the issues considered in a discussion of genetic testing for predisposition to addiction.





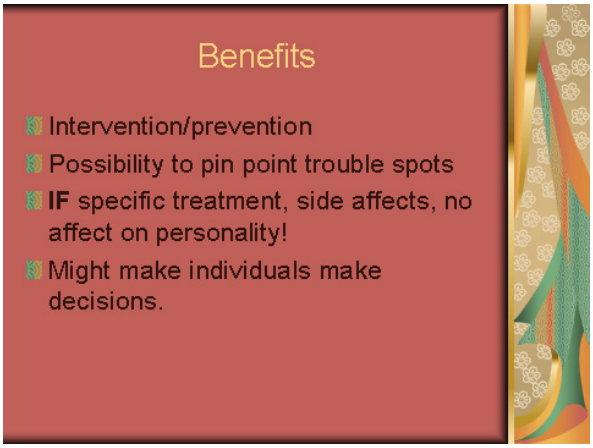
Participants were happy to accept that addiction might have a genetic basis in some cases. However, they were concerned about the consequences that might follow from using genetic testing to determine predisposition to addiction. Many of the issues they raised have been discussed already. Two that recurred were responsibility for one's actions – addiction is seen by many as a choice – and the limited control that someone would have over the environmental and social factors that might trigger the genetic predisposition.

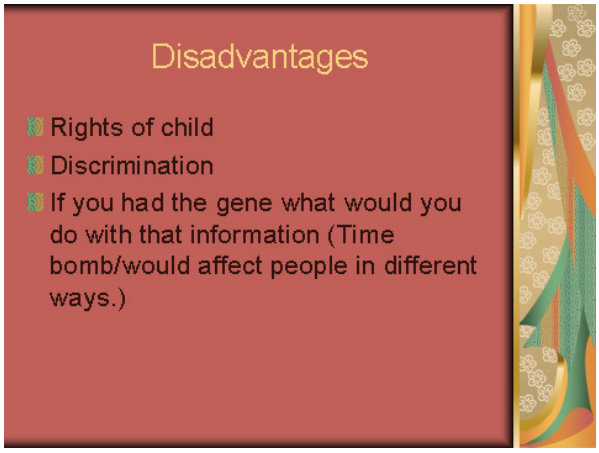
The question of 'positive addictions' arose in several discussions about testing and anti-addiction drugs. In the Exeter outreach work with drug users and ex-users, participants argued that addiction to power, work or other activities were also possible and that unless addiction was better understood, developing tests for addiction and ways of preventing it could have serious unintended consequences.

Benefits

The two slides below show the views of participants in the Exeter workshop on the benefits of testing young people for a genetic predisposition to addiction. Knowing that your child is more vulnerable to addiction than her or his peers would give parents an opportunity to intervene in a more directed manner and to inform themselves about environmental and social factors that might lead to the expression of the genetic predisposition.

[19] These quotes are taken from the Information Logs completed by individual participants in BB2.





These benefits were also identified by on-line participants. They went on to suggest that the consequences of targeting resources might include the prevention of addiction in people with an identified predisposition, and better treatment for those already addicted. They saw too the prospect of improved understanding of the causes of addiction that could also contribute to prevention and treatment. Finally, agreeing with some of the participants in the face-to-face work, on-line respondents felt that genetic testing might contribute to more social acceptance and sympathetic attitudes towards those with addiction problems.

For the test to have any value, however, it had to be taken in the context of other forms of support being available, such as help and information for parents. One advantage of the test was that it was seen as placing responsibility for avoiding addictive drugs on the individual and their family, since the possible impact of their decisions would be more certain than it might be in the absence of a test. However, this view was applied to positive tests only and was not held by a majority of participants.

> *'An awareness of a tendency to develop addiction could allow prophylactic measures to be taken – knowing that development of an addiction is a possibility can only further caution people against taking part in potentially addictive behaviour… A better understanding of addiction could lead to a better standard of treatment and management, particularly from a healthcare perspective, where there is still a lot of prejudice. Proof that addiction is genetic would change a lot of opinions, particularly when dealing with intravenous drug users in a hospital environment, where there is a lot of mistrust and prejudice.' (on-line participant)*

Disadvantages

The group from Exeter who looked at the benefits of testing for vulnerability to addiction looked too at some of the disadvantages, many of which were also identified by participants discussing this issue in other locations. Some participants suggested that testing a young child for addiction would trample on their rights, since a child would not be in a position to give informed consent. There was also concern about the results of the test leaking out, who would decide on whether or not to act on the results, and what actions should be taken. Even if the results of a test were supposed to be confidential to the child,

their doctor and family, people felt that it would *'get around'* and might lead to the child being discriminated against, teased or bullied.

Being labelled was seen as one of the prime disadvantages of taking such a test. This was an issue that also arose in the discussion of early diagnosis of mental health problems. Participants felt that those identified as 'positive' might be seen as somehow different and probably inferior to those identified as 'negative' for addiction. Some participants questioned whether addiction could be proven to have a genetic basis and cautioned against losing focus on the social and environmental factors.

> *'I would not like to see a child labelled an addict before a problem has occurred.'*
>
> *'May be [test] just those with family background but still not sure – would need to know more about it.'*
>
> *' [Test] all children.'*
>
> *(All quotes above from BB2)*[20]
>
> *'I feel that genetic tests of this sort could lead to a divided society – on one side a very smug group who know that they are unlikely to fall foul of an addiction, and a miserable group of people always wondering what their addiction is going to be. Worse than this, if tests were available before birth it is possible that some unscrupulous people may arrange for otherwise healthy babies to be aborted.' (On-line participant)*

The presentation below, developed and given by participants in the Belfast workshop, looks at the impact of being identified as susceptible to addiction on the individual and their family. Benefits for the individual include receiving relevant help, advice and support. The comment about 'knowing I am not alone*'* implies the possibility of a more open attitude towards addiction, with the stigma reduced sufficiently to allow someone to talk honestly about their genetic susceptibility. Another advantage for a young person identified as susceptible is the time it might allow for them and their family to consider what this means to them, and the most appropriate response.

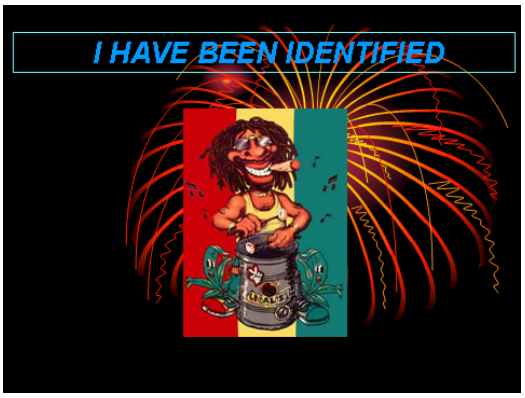
Ignoring, denying or rebelling are amongst the negative responses to being identified as vulnerable to addiction. Rather than taking positive steps to inform themselves about what identification might mean, participants think it is possible that an individual might resist the implications of testing 'positive' and refuse to accept the findings, or act in ways that further increase their susceptibility. Participants raise the concern about how affordable the services would be that were needed to support a child or young person identified as 'positive'.

Looking at the impact on the family, participants saw more negatives than positives. The negatives are focused around anxiety about the response of others to a family with a child identified as susceptible to addiction. This reflects the general feeling that there is a stigma

20 Quotes taken from individually completed Information Logs completed by participants in BB2.

attached to addiction. Parents and siblings might feel embarrassed, wish to move away or feel like outcasts within their community. They might also feel guilty, blaming themselves.

More positively, a family might develop a better understanding of the implications of testing 'positive', so enabling them to intervene and support their child more effectively.



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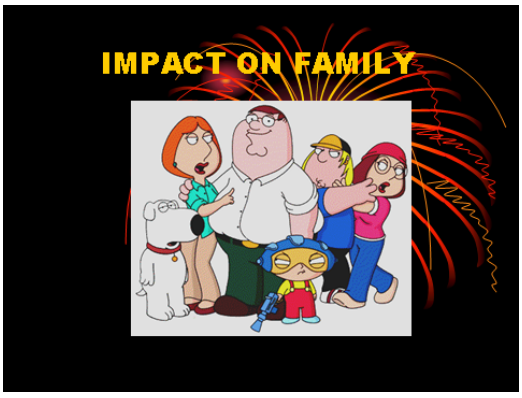

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Anti-addiction vaccines

Participants were asked for their views on the benefits and disadvantages of developing vaccines for use on babies identified genetically as vulnerable to addiction. The great majority thought that this was a dangerous step and would provide few benefits. The concerns raised were very similar to those explored when addressing the issue of genetic testing. Many described the use of a vaccine against addiction as a form of 'social engineering' and spoke of fascism, Nazism and eugenics.

Most people see starting and stopping the use of recreational drugs as a choice, and a great majority of participants think that this choice should remain open. Some participants felt too that overcoming addiction could have positive consequences for an individual.

Vaccinating babies against addiction is seen as limiting their future freedom of choice. The possibility of the vaccines being used by older people – one suggestion was from age 16 and up – was received more positively. People of that age would be able to digest the pros and cons more easily and make an informed choice. Questions arose about the nature of the vaccine itself, including whether it was a one-off or something that would need repeating, and what the side effects might be. Answers to these might impact on people's views.

> *'Using a vaccine for babies is trying to treat something that hasn't happened and might never happen.' (Exeter workshop)*
>
> *'Haven't we been here before…blond hair, blue eyes…?' (Exeter outreach – teachers)*
>
> *'Would it stop people from having addictive natures? Would the vaccine prevent people from being addicted to power, where would all the politicians go? And our great leaders?' (Exeter outreach – user/ex-user group)*
>
> *'What if we realised that everyone has the genes? What else would it block? Would it block the effect of the experiences. It is a bit akin to lobotomies.' (Exeter outreach – user/ex-user group)*

New drugs for new conditions?

Participants were asked whether there were any mental health problems for which new drugs should be developed in the future and to consider whether drugs should be developed for 'conditions' that are currently seen as aspects of personality, such as shyness.

A majority of participants suggested improving or developing new drugs for existing conditions such as dementia and depression, with many focusing on reducing or eradicating side-effects and contra-indications. Some argued that attention should focus on developing drugs for conditions that were most widespread in society, and whose alleviation would bring the greatest benefits to the greatest number of people. A number of people felt that improving existing drugs should take priority over developing drugs for any newly identified mental health problems.

> *'A few treatable mental conditions exist which could benefit massively from better drug therapies: conditions of aging (Parkinson's , Alzheimer's, etc.), and acute somatic distortions (schizophrenia, etc.) Some may not be curable!' (on-line participant)*

> *'Better drugs should be developed for the serious conditions that exist today – not creating new drugs for conditions that are a bit 'wishy washy' or may just be symptoms of a dysfunctional society rather than real illness.' (on-line participant)*

Conclusion

There was some support for genetic testing, though for many, their support was contingent upon the relevant information and support being available to people who were tested. Concerns were raised about whether those who tested 'positive' for a genetic susceptibility to mental health problems or addiction would be labelled and, in the future, whether foetuses with this susceptibility might be aborted. And if they tested 'negative', would people assume they were therefore immune?

Resistance to 'anti-addiction' vaccines was heartfelt. Participants spoke of fascism and the removal of future choices from those not yet at an age to make those choices themselves.

Rather than developing new drugs for new mental health problems, participants focused on the need to improve drugs for dementia, depression and schizophrenia and, in particular, to eradicate what can be debilitating side effects.

11. The future

Introduction

The hopes and concerns expressed by participants in this project could be used to describe two broad futures. Not every element of these was subscribed to by all participants. However, they do serve to provide an overall picture of the majority's hopes and concerns, and their priorities for achieving the positive future they envisage.

In this chapter, these two futures are sketched out. Following this, we look at the hopes, concerns and priorities on which these futures were based. Participants looked at the three classes of drug and, for each, developed a series of priorities for research, education and information, control and regulation and service improvement and development.

A bleak 2025

One possible future is dystopian, developing out of what participants think is wrong with our current attitudes and approaches to mental health problems, mental health drugs and recreational drugs, and their concerns about cognition enhancers. This negative future is beset by a number of problems. Problem use of licit and illicit recreational drugs is increasing and there is a general tendency to seek the fastest, probably pharmaceutical, solution to mental health problems, though the origin of many of these problems is seen as social rather than physical. It is a future infatuated by competition in education and employment, with cognition enhancers used to gain advantage in the race for success. The pharmaceutical companies spend heavily on marketing drugs for anger, shyness and other irritating characteristics that make you stand out as 'different'. Children are tested in the womb for predisposition to addiction and some are aborted before birth. In this future, being old or having a mental health problem heightens your risk of being controlled by drugs. This is a cheaper option than looking for cures. There is a lot of research into the development of drugs to treat conditions but little on understanding their origins and preventing their occurrence. The prisons overflow with addicts and adults with ADHD.

> *'There will be a shift in the idea as to what is normal and then more children will have to take drugs.' (Exeter workshop)*
>
> *'This is a slippery slope – it'll end with the abortion of 'addict' foetuses.' (Exeter workshop)*
>
> *'We're breeding a generation of zombies and losing childhood.' (Liverpool workshop)*
>
> *'We'll be on a total war footing and lock people up – or we change the system.' (London outreach – users group)*

A positive future

Perhaps the most telling aspect of the positive future is a change in attitude.

The stigma attached to mental health problems, drug use and addiction has gone. Research has led to the development of drugs for mental illness that have minimal side effects and are prescribed only when necessary. The side-effects of drugs for those whose condition requires them are minimal and well explained on medication packaging and by the prescribing physician.

Recreational drug use has not disappeared, something seen as unrealistic. But it is much safer now. Health, rather than punishment, is the framework for supporting those whose use becomes a problem, and the services are widely available and of high quality. Primary care and community health workers are as experienced in working with addicts and people with mental health problems as they are in helping someone with a broken leg. All children receive effective education on drugs of all types and on the issues that play a role in decisions about their use. This is provided in schools and in social facilities that are available for all children and young people, and delivered by young people themselves, users and ex-users. The penalties for larger dealers are harsh and are applied without question. Only those users who commit crimes wind up in prison.

It's better growing and being old too. Focused research on the causes of Alzheimer's Disease and schizophrenia has given scientists a good understanding of their causes. Although they have not been eradicated, the steps that can be taken to minimise their likelihood are widely understood and followed by the public. Other forms of treatment and support exist for mental health problems whose aetiology continues to present a puzzle and which resist pharmaceutical approaches. Treatments in the positive future are wide-ranging in type and available to all who need them, including the families of people with mental illness. Doctors and patients work together, with families and carers where necessary and beneficial, to work out the best course to take.

One thing that remains obscure about this positive future is how drugs currently classed as 'illicit recreational' will be distributed. They might be bought through not-for-profit outlets, in restricted quantities. This means purity is assured and the crime and violence associated with the black market are greatly reduced. Or only some will be available legally, such as cannabis, perhaps, with the harder drugs remaining illegal. Or it might be that the classification has been redrawn on the basis of research into the individual and social harms associated with the use of the various substances. All currently illicit drugs remain controlled and available only on the black market. No doubt there will be new 'recreational' drugs available too.

This positive future does not present a 'wish list'. It does, however, illustrate with a broad brush the thinking of a majority of participants who took part in this project. This chapter outlines participants' specific hopes, concerns and priorities for our future approach to the three classes of drugs: mental health, recreational and cognition enhancers. Because much of the discussion in all three areas focused on the place of drugs within the wider social context, rather than on drugs alone, their priorities include social, educational and environmental issues as well as those relating directly to drugs.

Hopes, concerns and future priorities

Continuing the conversation with the public about new drug developments and developing policies that take account of their views are seen as fundamental to achieving the positive future. Assuaging concerns about new developments in drug technologies leading to a society of control, from which diversity, idiosyncrasy and eccentricity have been eradicated, will require transparency in the policy-making process. Many groups will have an active role and some influence over the direction in which policy in this area moves, including drug companies, scientists and scientific institutions, the public, the police and health services, and specific groups, such as recreational drug users or people with mental health problems.. Public support for legislation is essential.

> *'Make powerful public figures more confident about telling the truth.' (London outreach – users group)'*
>
> *'Who is driving this research and why?' (BB2-IL)*
>
> *'[Have a] jargon-free dialogue.' (BB2-IL)*

Conversations such as the one that has led to this report can themselves be viewed with suspicion, illustrated by a question from a participant in Brainbox 1. The topic was cognition enhancers and the facilitator had been playing devil's advocate in the face of the negative response to this new class of drug. Rather than responding to the suggestion that there might be benefits in healthy people using cognition enhancers, one participant asked if it was really the case that these drugs were already out there and that the project was in fact being done on behalf of a drugs company looking for ways to sell them. Why, otherwise, would we be interested in their views? Explaining the value to policy makers of understanding the thoughts and opinions of the public on these issues in advance of making decisions about them went some way to addressing his suspicion, but did not remove it completely.

> *'Is there a hidden agenda behind this? We need to make an informed judgement about what is on offer.' (BB1)*

The hopes, concerns and priorities outlined below need to sit within the more general wish of the public to remain involved in the conversation.

Mental health

The table below lists a series of hopes for the future identified by participants who discussed drugs for mental health, as well as their existing concerns. The stigma attached to mental health problems and what was seen as widespread use of drugs when other approaches might be more beneficial, were two issues of concern to a majority of participants.

Hopes	***Concerns***
That the range and availability of other forms of treatment for MH problems will increase, including support for children with ADHD	An increasing range of conditions are being viewed as mental health problems
That the stigma attached to mental health problems will be reduced	The MH drugs are sometimes used for the benefit of doctors/society rather than of the patient
That scientific and medical research will generate MH drugs with fewer side effects and at different strengths (only option at moment is 'full strength')	'Normality' is becoming more narrowly defined
That 'dual diagnosis'[21] will become more widely available	That people with mental health problems have to reach crisis point before they get the services they need
That services will improve for people with mental health problems who are also using recreational drugs	That it's too easy to get a prescription for anti-depressants
That more research will be done into the causes of ADHD – eg, chemicals in food and environment	That an increasing number of children are being diagnosed with ADHD and prescribed Ritalin
Cautious welcome for genetic testing for MH conditions – but more research needed	MH conditions are too complex for a vaccine or other preventive measure to be developed

21 'Dual diagnosis describes people who have mental heath problems and drug or alcohol problems. The mental health problems may include schizophrenia, depression or bipolar disorder, or personality disorder.' (Definition from Rethink, a national mental health charity: http://www.rethink.org/about_mental_illness/dual_diagnosis/index.html, accessed 28Mar07)

Research priorities

Throughout discussions of mental health, a number of priorities for research emerged.

Mental health problems

- Develop a better understanding of the physical and social causes of mental illness and the factors involved in it, including the role played by:
  - Environment
  - Lifestyle
  - Diet
  - Food additives
  - Social stress/pressures
- Give priority to research into dementia and depression. Focus on the early stages and preventing progression
- Conduct research into the relationship between mental health problems and recreational drug use
- Conduct research that will help us to understand if and why any particular groups of people are more prone to mental illnesses, for example women and people from particular ethnic backgrounds

Drugs

- Focus on developing drugs that are effective and have minimal or no side effects or long term effects on general health
- Drugs that will prevent the emergence or progression of Alzheimer's Disease are crucial, given our ageing population.

Service improvement or new services

Participants outlined a number of priorities for improved services. In discussion, they did acknowledge that there would be resource implications here, but felt whilst there might be initial up-front costs, in the longer term, money would be saved because more people would be able to continue working and not need long-term drug treatment.

- There should be better, more widely available and varied alternative approaches to drugs, available on NHS, including:
  - Cognitive behaviour therapy
  - Drop in centres
  - Support groups

  - Counselling
  - Back to work activities
  - Coping mechanisms
  - Education, prevention
- More funding, provided by central government and by drugs companies, should go into mental health services
- Integrate mental health services and primary care more effectively
  - health centres should accommodate mental health facilities
  - mental health nurses in all doctors surgeries
- Educate and inform GPs about mental health problems and the range of support and services available in their area.

Reducing stigma

The stigma attached to mental health problems was one of the first issues raised by participants. Eliminating it is seen as fundamental to improving the lives of people with mental health problems and those who care for them. Suggestions include:

- Using famous people as examples. Stephen Fry, Tony Hancock and Paul Gasgoine were mentioned
- Provide more ways in which people with mental health problems can ‘re-learn’ skills or re-integrate with their community, for example:
  - Volunteering opportunities
  - Social activities
- Make it clear that mental health problems are not the preserve of any particular type or group of people: all classes, ethnic groups and age groups are vulnerable to mental illnesses

Increasing knowledge and awareness

The chapter on mental health highlighted participants’ view that mental health problems were ‘invisible’ and surrounded by misconceptions, suspicion, shame and fear. Increasing understanding of mental illness amongst the general population is seen as necessary to help bring it ‘into the open’. More information for patients on the drugs they are prescribed and other forms of support are also important.

- The information on prescribed drugs provided by GPs and in the drug packaging should be easy to understand, free from technical terms and large enough for people to read

- General awareness-raising campaigns should help inform people of the range and nature of mental illness. This could be done through print and broadcast media, doctors' surgeries and other public places
- Encourage more sympathetic treatment of mental health problems in TV programmes, soaps and dramas
- Promote positive mental health and awareness of problems through education in schools, for example, how to avoid depression, how to spot the early signs of dementia
- Hold more workshops such as those run as part of this project to provide people with time to think about these issues
- Aim information at patients and family members to ensure they all gain a better understanding of mental illness

Dual diagnosis

The relationship between mental health problems and problem drug use was the subject of sometimes quite heated debate, with participants discussing which should take priority. Ensuring that the necessary services and support are in place to help both drug users who develop mental health problems and people with mental illness who use drugs to help them cope or mask their pain is seen as important.

- Services providers should be competent in both addiction and mental health problems. They should ensure they understand whether mental health problems predate drug problems or are caused by drug use, and treat them appropriately
- The role of social, economic and family circumstances such as housing should be taken into account when developing support for an individual.
- Making sure harm reduction information addresses mental health problems is important

Recreational drugs

This class of drug includes licit substances such as alcohol and nicotine and illicit substances such as cannabis and heroin. Participants felt that the increasing use of alcohol amongst young people was a particular problem. Clarification of the drug classification system and effective education are two priorities.

Hopes	***Concerns***
That the drug classification system will become less confusing and more consistent	Confused and inconsistent messages sent out by government in relation to drugs
That drug classification will take into account the harms of particular drugs	Adult hypocrisy in relation to drug use – adults use alcohol and nicotine freely
That legal penalties will be more equally enforced (eg, applied to celebrities as well as 'ordinary' people)	That current drugs education does not seem to be working

Hopes	*Concerns*
That a health-based approach to drug use will be developed	That school is not the best place to deliver drugs education to children and young people
That peer education and education programmes involving drug users and ex-users will be developed	That very young children are quite knowledgeable about recreational drugs
That drugs education will start at primary school age	Testing people for genetic vulnerability to drug addiction may lead to it being seen as a disability
That support services will be universally available to all children and families – this will stop people being labelled as a problem / potential problem	Parents whose child is identified as vulnerable to addiction may become over-protective
	That information about genetic vulnerability to addiction will not be kept secret
	That an 'anti-addiction' vaccine for use in cases of genetic vulnerability will remove choice from people

Research priorities

The consequences of ending prohibition were debated in some detail. A majority of participants were not in favour of this, preferring a system of classification similar to that which exist now, but informed by real information on the harms of different drugs. However, they did think it would be worth doing research into different distribution methods.

- Gain a better understanding of the potential consequences of taking drug distribution out of the black economy, for example, by allowing legal purchase from licensed distributors such as a chemist shops or not-for-profit outlet
- Involve drugs users in research much more, since they have considerable knowledge and experience
- Research into the positive effects on mental health problems of currently illicit drugs
- Do more research into how addiction can be prevented
- Research the value of non-drug based approaches to addiction such as exercise or counselling, rather than focusing only on 'blockers' or 'anti-addiction' vaccines

Priorities for service improvement and new services

Focusing on health, rather than punishment, as the most effective approach to problem drug use, participants advocated a number of improvements to existing services.

- Ensure that health services are available to and accessible by addicts. This should mean all health services and not just those specific to drug use.
- Focus on harm reduction, and provide resources to organisations and projects that adopt this approach, for example, user galleries and projects such as The Relay Project

- Ensure widespread availability and accessibility of services to those who need them
- Develop community-based services to deal with issues at local level
- Have support mechanisms in place for the families of addicts including alcoholics
- Prescribe pharmaceutical grade heroin to users

Priorities for education and information

Effective education was seen as something needed by the population as a whole, though efforts at prevention focused on young people. It was seen as incorporating a number of features.

- Ensure information is honest, open and clear about the benefits as well as the disadvantages of recreational drugs, including alcohol and nicotine
- Provide information and education for drug users and addicts on the health implications of drug use and how to minimise harm
- Education should cover the effects of drug abuse on home, work and society, ensuring the dangers are properly understood
- Involve ex-users, addicts and alcoholics in drugs education, rather than the police
- Develop effective peer education programmes
- Develop drugs education for out-of-school venues, for example, in recreational venues, clubs etc
- Start drugs education at a much earlier age, with information and approach tailored to the different age groups
- Use education to remove the stigma of taking recreational drugs
- Have TV adverts of help available so people know where to go.

Control and regulation

As has been noted already, a majority of participants supported continued prohibition but favoured a health-based approach to drug use, with imprisonment for dealers and traffickers.

- Reduce the dominance of legal sanctions against drug users
- Have more areas that drug users can use safely without harming society
- Acknowledge that it is impossible to eradicate the use of recreational drugs
- Control quality and ensure greater purity by introducing user galleries
- Crack down hard on dealers and remove their assets

Cognition enhancers

The chapter on cognition enhancers highlighted the different nature of the discussion of this class of drugs. This was attributed to their newness, which meant that participants did not bring ready-formed views to the debate, but explored their own attitudes during the workshops and discussions. The overall view was that further research needed to be done into their effects, both immediate and longer-term, before policy should be made either prohibiting or allowing their use amongst the 'healthy' population. The greatest concern, as with the use of recreational drugs, was their use by young people, whose brains are still developing. There was wide support for use of cognition enhancers by people with recognised mental health problems such as ADHD and dementia.

Hopes	***Concerns***
That more research will be done into the use of cognition enhancers for people with Alzheimer's and dementia	If cognition enhancers become widely available to the general population, this will widen inequalities (eg, poorer people won't be able to afford them)
That improved and more widely available cognition enhancers for people with MH problems associated with ageing will improve the overall health and wellbeing of older people	That cognition enhancers will change people's personality
That more research will be done into the effects of long-term use of cognition enhancers on healthy people	That cognition enhancers could be used to control people
That we will learn more about the different impact of CE on different people	That Ritalin is already being used to control the behaviour of children, rather than putting proper educational support in place
That more research will be done into the impact of cognition enhancers on children and young people who are vulnerable to substance use (not just those with ADHD)	Create people who are pretending to be good at something but in reality they are not – dangers for some jobs?
May have value for shift workers, long-distance drivers etc	CE used by healthy people will help to reinforce already over-competitive environment – eg, parents forcing children to take them to get good grades, competition in the workplace etc
That the primary focus will be on helping people who are ill rather than enhancing the well	Not enough is known about the effects of drugs yet

Research priorities

Participants felt that much more research should be done before policy could be developed on the use of cognition enhancers by people without medical need. This would include both scientific research and research into the potential social and economic consequences of widespread use of cognition enhancers by the population in general.

- Research should focus the benefits of cognition enhancers for people with mental health problems, including dementia and ADHD
- Research should be done into the effects on ‘healthy’ people of short term use, cessation of use and long-term use
- Research should be done into the effects of abusive use of cognition enhancers, eg, the possibility of addiction
- Research should be done on the effects of cognition enhancers on the developing brain
- The social and financial impact of widespread use of cognition enhancers should be explored. Government should lead the research, in partnership with private sector

Conclusion

The hopes and concerns expressed by participants throughout this project have been drawn on to sketch out two futures, both of which are seen as possible. Their priorities focus on the steps they feel are needed to ensure that the competitive and narrow future is not realised.

12. Conclusion

It is not possible to draw conclusions, at this stage, on the overall success of this project. Without the evaluation report, the views of participants should not be the subject of speculation. The project team has not had time to reflect in any detail on what we have learned from the work and how we might do things differently if similar opportunities to work together arose in the future or what new understanding we bring to our own individual work. The final objective of the project was to 'enable the AMS and the wider science community to increase their knowledge and understanding of public engagement and its potential for future application.' Fulfilling this objective will have to wait until the evaluation is done and the project team has talked.

Enough has been said already about the content. Perhaps the most apt conclusion is just to say thank you to everyone who has been involved with this project.

Most importantly, thank you to the people whose views are recorded here, for their enthusiasm and considered views and for relating some very personal experiences.

We would like to thank the experts for giving their time and knowledge to the project. In particular, to Robin Felton and Rebecca Swift for stepping in at very short notice to give presentations at Brainbox 2 and to The Relay Project in Liverpool. The Relay Project organised an outreach group in Liverpool for us at the very start of the work and some of their members attended the Liverpool workshop. The fantastic presentation given by Sue Garratt and Keri Tozer at Brainbox 2 was developed with input from the whole Project.

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