
What
Harm Reduction
Mean To
You ?


1ST SCOTTISH HARM
REDUCTION CAFE

Report

Scotland's First Harm Reduction Cafe

This report is intended to support anyone wanting to host a harm reduction cafe in their local area. It offers useful learning and guidance as well as giving a summary of some of the outputs of the first harm reduction cafe in Scotland held in Glasgow in November 2013. The primary source for resources on harm reduction cafes is the HIT Community Project, Harm Reduction Cafe. http://harmreductioncafe.com/ Anyone planning a cafe should visit this website.

If you have any questions or queries on the Glasgow cafe or the contents of this report contact Austin Smith, Policy and Practice Officer at Scottish Drugs Forum – austin@sdf.org.uk

SDF Scottish Drugs Forum

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Contents

Background

The roots and history of the harm reduction cafe

The roots of the harm reduction cafe are the roots of harm reduction itself – amongst activists / activist users and frontline staff and professionals. There are various cultural influences which shape harm reduction cafe approach including the Sceptics in The Pub movement. Nigel Brunsdon of HIT, who was key in initiating harm reduction cafes, explains some of the thinking, in a particularly English context, here - http://www.youtube.com/watch?v=raycjCoDlxY

Harm reduction cafes and recovery cafes

In practice these should be complementary and people should be able to benefit from attending both types of events. As mentioned in *The Road To Recovery*, there is a false dichotomy between harm reduction and recovery, sometimes based on a misunderstanding of the purpose of harm reduction and of what recovery is.

People committed to working to reduce the harms from which people have to recover should understand their role in recovery.

The harm reduction cafe 'movement'

All harm reduction cafes have been based on similar formats and processes and have been organised through http://harmreductioncafe.com/ which offers a free resource to anyone organising such an event. There have been dozens of such events across England, Wales and Northern Ireland… and even in Europe and America. The purpose of such an event is for people to share information about harm reduction and support each other in reducing harm whether to themselves or others.

The Event

Scotland's first harm reduction cafe

The first harm reduction cafe in Scotland was held on 26 November 2013 in the Brunswick Hotel in Glasgow city centre. The date was chosen because it was the evening before Scottish Drugs Forum's conference - *Frontline Response to Trauma; a key to recovery* and it was hoped that there would be synergies between these events.

Planning

Scottish Drugs Forum (SDF) decided to plan and host the event and sought partners to advise on and deliver content. Turning Point Scotland and Crew agreed to be partner organisations.

A venue was sourced. The management of the Brunswick Hotel was kind enough to offer the use of their function suite for free. The event was advertised on the partner agency websites, through social media and on the http://harmreductioncafe.com/ website at - http://www.harmreductioncafe.com/index.php/meetings/findmeetings/scotlands-first-hr-cafe

SDF's Kirsten Horsburgh and Katy MacLeod were named as contacts and sources for further information. Nineteen people registered to attend in the first 48 hours – suggesting that this was a timely and useful idea. The event was also advertised through adopting the excellent publicity materials downloadable from the http://harmreductioncafe.com/ website.

A few key staff employed by the partner agencies agreed the format and content of the event. Some materials were developed for use on the night by various stakeholder – e.g. the talking wall, discussion prompt sheets etc

The event itself

There was an unexpectedly high turn out with around 70 people attending on the evening. People came from across Scotland – from Greater Glasgow and Clyde, The Lothians, Forth Valley, North Lanarkshire, Ayrshire and Fife. There was a mix of people attending including people in recovery, health and addiction staff, family support staff and peers.

The cafe was set up in a conversation cafe format. There were six tables chaired by different representatives from the three partner organisations. People moved round the tables approximately every 20 minutes. Key comments were captured on flipchart and then used as discussion prompts for the following groups. Full details of the key comments and themes from each topic can be found in the appendices to this report.

The discussion topics were:

- Naloxone (led by Kirsten Horsburgh and Jason Wallace, SDF)
- New Psychoactive Substances (Katy McLeod, SDF)
- Hepatitis C (Lesley Bon and Graham Mackintosh, Hepatitis Scotland)
- Drug consumption rooms (Patricia Tracey and Kevin Hattam, Turning Point Scotland)
- Online support (Emma Crawshaw and Laura Dey, Crew)
- User Involvement (Norma Howarth, SDF)

Feedback from the event as a whole was recorded on A1 sheets by both attendees and facilitators. (See appendix seven) There was also a 'talking wall' titled "What does harm reduction mean to you" to which people added comment over the course of the evening. (See appendix eight).

Learning and suggestions for development

Organising an event

It is likely that a smallish group of committed individuals, from various organisations, or none, will be involved in the planning of an event. Where people are employed within the drugs field they will probably be working beyond the strict remit of their post. Consideration should be given as to whether an event is being organised by an individual or the organisation that employs them and of the implications of this. Of course, events could be wholly organised by people outwith the drugs field or who are stakeholders in roles such as being people who use drugs, being in recovery or people who are family members, friends or carers.

Invaluable free support is available at http://harmreductioncafe.com/ website.

Costs

A harm reduction cafe is unlikely to be an income-generating activity in itself and therefore will not be able to cover its own costs. While costs can be kept low, some form of sponsor or subsidy may be required. By organising a cafe with another income-generating activity, for example a conference or training event cross-subsidy and useful synergies may be possible.

A small group of committed individuals or organisations may be able to work together to source a free or low cost venue, catering, stationery or whatever else may be required; the larger the network, the more likely that someone will have a friend of a friend who can contribute resources. However, having a large and loose group of stakeholders may mean that detailed planning becomes more difficult.

Venue

The venue may dictate what possible format a harm reduction cafe takes. A venue that can cope with hosting a harm reduction cafe should not be difficult to find but compromises on the exact content and format of the event may have to be made.

Catering

If the event is after work people will need to eat. Some people arriving at the Glasgow event had presumed that free food would be available and had been unable to get a chance to eat after leaving work. If food is not being supplied this should be clearly stated to people who register to attend and/or through publicity materials. There may be an issue for some stakeholders about hosting a cafe on licensed premises. This issue should be considered in the planning process.

Format

The exact format is a matter for those organising the event and for people who attend. The Glasgow event featured a set of discussion groups which lasted for a fixed period after which people attending were free to join another discussion group. Some group facilitators repeated a similar format and topic for discussion each time; others had a series of topics they wanted to discuss; others asked each group what they wanted to discuss under the heading of the discussion title. The discussions were recorded by facilitators as they saw fit and they wrote up the report on the workshops as they saw fit (enclosed here as appendices).

Generally the format worked well although the attendance meant that the venue was full and this caused issues of noise etc.

Marketing and attendance

The event was marketed by the supporting organisations, through corporate and personal social media and in part using the harmreduction.com materials.

The event was over-subscribed and the attendance impressive given that this was an evening event in November and, as was pointed out, on a Champions League night! In a Scottish context it is also worth noting that the event was attended by many people from outwith Glasgow and from as far away as Fife.

The demand for such events is clearly demonstrated.

Outputs and outcomes

The discussions produced notes and commentary which may be of use in informing the work of participants and others including the organisations for which delegates worked. However, there was a far greater range of softer outputs. Positive feedback included an increased understanding of the basis, range and potential of harm reduction activity. Some participants described the positive benefit of being able to talk openly and unapologetically about issues related to drug use and harm reduction. People remarked on the confident and optimistic mood. It is to be hoped that some of this thinking and learning as well as some of the attitude will be taken back to workplaces.

There was some interesting feedback from participants in terms of their motivation for attending and some of their feedback regarding the event. Sadly, it is clear that people who have, or have previously, identified their activities as being focused around reducing harm have felt alienated from much of the discourse around drug treatment and recovery. They have felt their work to be excluded from notions of recovery. This has not been helped by the continuing stigmatisation of treatment and an uninformed 'debate' around methadone and ORT. This is a wider issue but harm reduction cafes offer an excellent setting for integrating some of the fundamental bases for a harm reduction approach with notions of what recovery might mean for services and for individuals. The importance of an informal 'badges off' discussion with informal face to face discussion with people across the drugs field cannot be over-emphasised.

Future harm reduction cafes in Scotland

Given the interest and commitment demonstrated, it is likely that future cafes could be planned and prove successful. Suggestions were made for topics on which these could be based – these included drugs and sex. There was an interest in harm reduction in its widest sense, the link and contribution to recovery and re-finding the roots of much service provision.

Appendix One – Notes on Naloxone Discussions

Many people with a huge variety of experiences relating to naloxone took place in discussions throughout the evening. They ranged from nursing staff actively involved in supplying naloxone, to people who had never heard of naloxone.

The general feeling was that the programme is well supported however there are still local barriers to be addressed. Some felt it was not yet normalised and that there is often a reluctance from people who use drugs to accept a supply from some services. There was a frustration from some nurses that not all colleagues were making naloxone supply part of their practice and that this needs to be resolved. Managers need to be on board was a common theme.

People felt that delivering the training needed to be opportunistic and brief, as group training could potentially be a barrier. This needs to be accompanied by "giving the right message" and people were in no doubt that this means having good relationships with people and reassuring them that accepting a supply of naloxone is a positive thing. One comment was that "people who are passionate will make it work".
Another thing helping to promote supplies locally is the increasing amount of uses of naloxone to successfully reverse overdoses in the community. This word of mouth is extremely beneficial in raising awareness of the benefits of take home naloxone.

Family members were represented and voiced their desire to have easier access to naloxone supplies, however there was also an agreement that receiving the training was just as important.

The Medicines and Health Products Regulatory Authority (MHRA) consultation was highlighted as an opportunity to have a say in what could allow wider access.

There were a lot of positive comments about the Naloxone Peer Education Networks and the need to see more of these networks across Scotland. It was felt that this approach massively increases the reach of the programme and is essential.

We were very fortunate to have a nurse able to make supplies of naloxone present and one person took up this offer. For future cafes this is something we will definitely look to develop.

Flip chart comments quoted from participants -

- Is it normalised?
- ? Some embarrassment not wanting to let people down
- Uses not always being disclosed
- Potential for relapse. Naloxone should be available
- Are we giving people the tools to allow overdose?
- Getting the message right!/More family supplies
- More uses creating awareness
- Nurses to increase supplies
- Needles being taken from packs, Lack of IEP?
- Less barriers/Initial problems with governance
- Fear of needles in packs
- Protocols, storage
- Naloxone does not encourage drug use!
- Groups=barriers
- Peer education the way forward
- People who are passionate will make it work!
- Emergency medication
- Perceived barriers
- Still some resistance
- Persistent and consistent
- 3rd sector peers+NHS working together
- People in recovery reaching “hard to reach”
- Emergency medication
- Restrictions for families
- Services anxious re. administering naloxone
- Encourage more involvement
- Prescription drug use
- Hard to reach=hard to provide

Appendix Two – Notes on New Psychoactive Substances Discussions

1. Perception of use

There was much discussion about the perceptions of legal highs particularly by young people. Some felt that they may feel legal=safe and that use is non-problematic due to the substances not being illegal. Sense that some young people find NPS more socially acceptable. Also discussion about people using who may be in recovery and feel that these are not "proper drugs" and perhaps unaware of risks of relapse etc. Older users may get "caught out". Marketing of many NPS feels tailored to young people.

2. Scale of use

It was highlighted, the wide appeal that these types of drugs have to many different user groups, all age groups! The focus is often on young people but it is not just young people using. Many people already in services are starting to use these substances.

3. Information and harm reduction advice

The challenges of there being limited information on NPS was highlighted as a barrier for services giving out information, sense that not enough information is known in services, little is known about long term effects and it is hard for workers to keep up. There is a need to give balanced and credible information. It's also key to look at poly drug use and attitudes towards this.

Questions that arose were: What information can you give to young people? Should we give harm reduction advice to young people? When do I start the conversations? The difficult balance of providing information vs. accidental promotion was highlighted. Many participants felt that scare tactics don't work with young people and that it was better to offer information for them to make more informed choices. Discussed that in many ways, this was similar issue to promoting safer sex messages to young people. Age appropriate harm reduction advice that meets people where they are at within their drug use experience is crucial in order to prevent drug related harm. Recognition amongst discussion groups that experimentation and taking risks is often part of growing up, challenges in how you support young people to really acknowledge risk and adapt their behaviours.

Also discussed necessary harm reduction advice for older and existing drug users who may believe they are very knowledgeable already about substances and therefore may not recognise need to access information on NPS. It's possible that some substances could be so risky that there is limited harm reduction advice to give out. Also as dose and substance may be unknown it is difficult to give advice. Generic harm reduction advice around test dosing and not re-dosing too quickly flagged as useful in almost every situation.

4. Prevention and education

It was felt that substance use education should be early, possibly in both primary and secondary education but certainly by age 12-13. It should also be better embedded in the whole curriculum e.g. through history, modern studies, biology, media studies etc.

Emphasis that harm prevention and education can't just focus on treatment in the same way as sexual health education.

Discussion of need for community involvement and potential benefits to community of being involved. GP's have a key role, information campaigns could be run on bus shelters, through pharmacies etc. Important to give co-morbidity information, not just about the drugs but other factors e.g. mental health, self esteem etc.

5. Challenges for family

Challenges for parents and family members were discussed, with young people often knowing a lot more that their parents about the substances around. Parents' reactions to NPS issues can be exaggerated; due to their unknown nature, they can feel more frightening. Important for parents to be open to all information coming from their children e.g. accept the reasons for use e.g. fun. Also about recognising balance between peer pressure/peer support from friends networks. Discussion about the impact on young people of parental substance use, can encourage some to stay away from substances or make them more likely to experiment.

Discussion of potential impacts on family members with people developing problems with NPS and where they could access information and advice tailored to them.

6. NPS and sexual and reproductive health

Risks to sexual health highlighted as a concern, issues such as unplanned sex, risky sex and regretted sex all key issues. Discussion about the risks of NPS use in pregnancy e.g. drugs like mephedrone are vasoconstrictors and can cause placental abruption. Highlighted the different drugs in use by some groups e.g. men who have sex with men taking more GBL, Ketamine etc.

7. Treatment and prescribing challenges

Integrated services such as Club Drug Clinic discussed as a possible effective way to reach NPS users. Discussion around techniques to engage "new" users, who may fit a different profile to traditional service users. Need for treatment to be soloution focused.

Discussed the lack of substitute medications for NPS and challenges of working in treatment services with a more medical model. Case study was given about a GBL user who was being prescribed benzodiazepines currently due to issues relating to withdrawal but whose goals for their GBL use was to return to more recreational using patterns rather than fully detox. Discussed implications with long term prescribing of drugs such as benzodiazepines and how treatment for NPS has to have a major focus on psychosocial interventions and harm reduction/tapering strategies in the absence of suitable prescribed medications.

8. Role of peer education/recovery stories

Discussion about how people with lived experience of drug use could help educate about risks and potential consequences of drug use.

9. Legality

Discussion about current legal framework, does banning help? Often feels like a catch 22- the quicker we ban, the quicker new substances are made. Legal challenges of licensing shops are similar to issues such as saunas. Suggestion of different models used by other countries e.g. New Zealand. Could we control sale in UK? License, least harmful products? General feeling that sellers rather than users should be targeted. One issue highlighted is that current legal situation prevents advice at point of sale as products “not for human consumption” Should vendors be able to give advice at point of sale? How could this be accommodated in current legislation? Would it be possible to ensure that drug services could put up independent drug information in headshops so that people could access harm reduction information without headshops being prosecuted for giving this info out?

10. Drug Testing

Recognition that some people are using NPS to beat drug tests, knowing they are undetectable.

There was discussion around the benefits of drug analysis not only for the drug users but also for the intelligence it can provide to professionals working in the drug and alcohol field. The Welsh WEDINOS project was discussed as a good example of practice developments in this area. The project involves people who use drugs being able to submit samples for testing via mail, police and hospital transportation scheme. They also submit an effects sheet which documents various useful information including what they thought they were buying intended and unintended effects and what other drugs they may have used. Results are then posted online 2 days later.

Appendix Three – Notes on Hepatitis C Discussions

1. New Injectors

Scenario: Somewhere in Scotland a young person is injecting for the first time and not accessing any services. How do we ensure this young person has information to minimise harm?

a. This information could be part of an induction package for services for vulnerable young people for example, supported accommodation projects incorporated into messages that may be more appropriate to them e.g. tattooing or snorting drugs. Even if young people are not currently injecting or involved in drug use, if the messages of safer injecting practices are given before risk taking behaviour starts – more likely to be embedded in their practice.
b. This generation of young people use social media as a key source of their access to information. Creating an app that gives harm reduction messages, signposting to services as well as information on how to use drugs to minimise harm may be a route to inform young people.
c. Embed messages of not sharing any drug taking paraphernalia into sexual health education within schools – linking with other sexually transmittable BBVs – and discussing possible other transmission routes.
d. Commission more age appropriate services for vulnerable young people – ensuring 17 year olds do not find themselves in accommodation projects with older adults.
e. Giving messages on minimising harms through drug taking could be given via different sources aimed at young people: Colleges, College Radio, Fresher's week, Education or work programmes for aimed at young people not in mainstream education, young offender programmes/ institutions, children homes etc.
f. Injecting NPS – new group of injectors – we need to learn messages in what is the safest way to inject – as some are water soluble and different to how you would prepare heroin. The occurrence of 'slamming' parties being reported in London and Glasgow gives greater concern with the risks of injecting NPS and many sexual partners.

2. Safer Injecting Practices

IEP services distribute, free of charge, needles, syringes, cookers, filters, acidifier, water for injections and pre-injection swabs to service users. The provision of such equipment is available with no restrictions in quantity, and clients do not have to return used equipment to be given new supply. However the supply of equipment does not equate to the number of injecting

episodes that occur – which means more must be done to ensure that for every injecting episode – new equipment is used each time.

a. Staff within NEX services should be actively enquiring into if clients are knowledgeable in safer injecting practices – and not to believe that the injectors know best. It is important to have the conversation with clients – even in low threshold services, when people want supply of equipment and to leave quickly – need to try quick interventions which may lead to longer interventions.
b. Pharmacy based NEX – staff need to be trained on the importance of the public health service they are providing – and to provide a more respectful service to clients.
c. As opposed to messages of fear – such as if you share equipment you are at risk of BBVs – staff can tailor messages in a more positive way, such as: Top tips for a more enjoyable drug taking experience – vein maintenance etc.
d. Staff need different knowledge depending on type of client: opiate injector, NSP, steroid, melanotan etc
e. Messages need to be given for isolated users – those who inject alone – at the risk of overdose and other drug related death risks.
f. Need to scope other countries models of best practice and find out what can be transferred to improve practice within Scotland whilst keeping in mind the cultural differences within Scotland and quality of drugs available. Example model to look at was the Dutch model.
g. Although NEX in prisons has been dismissed as a possibility – in an 'ideal harm reduction world' this would be a service provided – all other paraphernalia is provided except for needles/syringes – so the small number of in prison injectors use homemade equipment which is more readily shared.
h. Relationships where sharing of equipment does occur – need to be aware of the intricate negotiations that occur between partners – such as we share everything else / we have intimate relationships etc Power is often seen as a precursor in these sharing relationships. Being able to show the much higher risks associated with sharing injecting equipment with couples who have a sexual relationship may have an impact, however it is much more difficult to alter a learnt behaviour than providing this information to people before they begin to inject drugs.
i. The provision of foil from NEX in 2014 will make having conversations with clients easier in terms of moving from injecting to smoking.
j. Staff involved in IEP services need to learn to shout about the positives that the work they are involved in has accomplished – thousands of lives saved and infections prevented.

3. Examples of Prevention

a. **Treatment as prevention** - giving early treatment to small numbers of people who inject drugs and are infected with hepatitis C, will prevent the need to treat larger numbers later, reducing the risk of injecting drug users suffering from liver cirrhosis and cancer which can develop over time if hepatitis C remains untreated.
   - A £2.2 million project to tackle the spread of hepatitis C infections among drug users in Tayside has been launched by Dundee University and NHS Tayside.
   - Different criteria for treating current drug users in different Health Board areas. Some boards contraindicate drug use and Hep C treatment, where as other boards do not.
   - University of Bristol and London School of Hygiene and Tropical Medicine used mathematical modelling to show that *"chronic HCV prevalence among PWID could be halved in 15 years by doubling HCV treatment in Edinburgh to six per cent among PWID with chronic HCV"*
   - Treat more now to prevent treating many in the future – and reducing end stage liver disease for PWID

b. **Break the Cycle Campaign** – aims to prevent current injectors from discussing or showing injecting of drugs to non-injectors in the hope this will prevent non-injectors from starting.
   - Discourages bad practices from current injectors
   - Current injectors don't want to feel responsible for initiating new injectors

c. **Targeted Training –** training aimed at different groups and the staff who work with them:
   - Prevention education can be tailored for different audiences – Schools, Tattooing, PIEDS, Sexual Health, Prison, Current Injectors, vulnerable young people, sex workers, homeless etc
   - Staff are provided with appropriate information – if they are not given tailored training, there can be fear of providing the wrong information, so don't provide any information.

d. **Needle Exchanges** – Providing foil will create an opportunity for reducing harm, by talking to users about the benefits of smoking over injecting.

e. **Alcohol Prevention in Schools** – A route for providing harm reduction messages
   - Discussion of poly drug use – linking to bbv risks
   - Age appropriate information given

f. **Providing travel expenses** and travel warrants to reduces barriers of accessing services. Not providing these can mean people are unable to get to services they need.

g. **Support after treatment:** During a treatment regime, either for drug addiction or hepatitis C treatment – will provide in depth support that can be taken away once the treatment has been stopped. This can be a vulnerable time in a person's recovery – its important adequate support is still available to those who need it.

h. **HBV Vaccination** – vaccinating current drug injectors against HBV is a key way to keep engaging, providing prevention messages, and opens the door for further prevention work.

i. **Drug Consumption Rooms** – can change practice and behaviour of injecting drug users by having trained workers available to educate on any bad practice that occurs, provides opportunities for intervention and given of harm reduction messages.

Peer Education Programmes

Why utilise peer education programmes?

Peer education programmes may have a number of benefits including an ability to engage opportunistically with harder to reach groups, provide messages that may be perceived as more credible, and modelling of positive behaviours. There is also the benefit to the peer educators themselves in terms of understanding issues better and enhancing their own confidence and skills. The broader impact of peer educators engaging positively and re-integrating into local communities can help challenge negative societal attitudes and stigma.

Prevention

The change talk model, which was piloted across three areas, identifies and recruits those with personal experience of substance use. Incentives are offered to attend training to become a peer educator and relay key health messages to other peers in their network. Peers who receive these messages are provided with a token with which they can present at services / IEP and receive an incentive if they can recall the key messages.

The change talk model had an impact on the peer educators knowledge and attitudes however it did not show significant impact on influencing peers. It was considered that the approach still had merit if the design, training, support could be modified. Suggestions included a more concise matching of peer educator to peer e.g. peer educators in recovery could link with those entering/ currently in treatment whereas current injectors with good knowledge/practice could target those who are still actively injecting.

In addition to focusing on specific issues such as key health messages peer educators can also provide more generic information e.g. signposting people to relevant services and recovery orientated services such as conversation cafes.
It was suggested that peer educators could access clusters of peers via existing support groups/mutual aid groups and provide specific messages e.g. provision of information on testing, treatment, and support of Hepatitis C.

It was recognised that informal peer education may occur as service users opportunistically disseminate a wide range of information they receive from a variety of sources. Although we may be confident this happens it is very difficult to gauge the extent, quality and impact of such interventions.

Peer educators could also provide information/support on lifestyle changes for people living with Hepatitis C and family members and provide buddying support for those going through the care pathway.

Although it was recognised that financial incentives may be a useful tool in the recruitment process, of both peer educators and peers, it was also acknowledged that other factors could attract people and engender participation e.g. the opportunity of participating in a positive activity, developing and enhancing skills, putting something back into local communities.

Appendix Four – Notes on Drug Consumption Rooms Discussions

Majority of conversation positive about introduction of these rooms. Some people had not heard about the concept before and were concerned about public perception. Others raised issues around more services being targeted at heroin use (although it's the only substance injected) and felt there were already services for that substance and more services were needed for other types of drugs. Others felt that the evidence was there and some real pressure and public campaign was needed in Scotland to get these introduced and they felt frustrated that these are discussed and there is evidence but there is never any action. The discussion did raise questions about quality for harm reduction being provided in services at present in particular vein care.

Fipchart Comments

- Step not answer
- For a specific group
- Issues with police presence
- Who would delivery
- Staff burn out
- Building therapeutic relationships – eventual intervention route
- Learn safer practise then share knowledge woth others – cascade
- Good idea to have no-one alone when using
- Where? How? Who?
- Isolation removed
- Good practise shared
- No-one uses heroin any more
- Harm reduction and recovery part of the same continuum
- Support from peers in the room?
- Recovery workers in the rooms?
- Who would staff?
- Overdose!
- Where, how?
- RIOTT trial
- Ideally would have medical professionals and supplies and people in recovery in DCRs
- Cant even get drug litter bins
- Not just a 9-5 service
- Evidence of worth in other countries – what's stopping us
- Need support attached
- Learn from Brighton
- Vein care
- Accept stabilisation as a goal
- Legalize heroin
- Stop putting plasters on
- It's time for real discussion
- Public campaign needed

- It’s a no brainer
- It’s a human right
- Pathway to support
- Staff can intervene
- Reduce drug litter
- Safe environment
- Reduce public injecting – effect on community
- Reduce overdose

Appendix Five – Notes on On-line Support Discussions

Stigma

Stigma attached to drug use – online resource 'safer' for people. Online support helping to break down stigma and good for those who are maybe not ready to or wouldn't consider accessing drugs service – e.g. experimenting etc. Stigma attached to accessing services, especially women and people with children – online services offer a way around this as a first step to engagement. There is perhaps more stigma accessing support for illegal drugs than NPS, risks may also be perceived as less for NPS.

Access

Clear benefit of online support is accessibility for those who perhaps can't attend a physical service. People may access online support who wouldn't access a physical service. Could also facilitate access to face to face services and recovery support. Online offers out of hours service.

Information

Big difficulty especially with NPS of getting up to date info for workers and service users. People are expressing concern about perceived number and ongoing emergence of NPSs, constant changes in which NPS are about and are in use, how much we actually know about NPS-an online advice service good for this as can quickly adapt (although bear in mind that some agencies can't access anything containing drugs terminology online). Important to myth bust- legal highs won't necessarily be legal or safe. Also important to account for regional difference in street names for drugs. It's important to have consistent messages. Materials and information needs to be age-appropriate. Sources of information are key, should be gathered from a variety of sources including people who use, alerts, internet experience reports etc.

Crew's online service MyCrew www.mycrew.org.uk was highlighted as a national resource which could be accessed. Harm reduction is core to Crew's ethos and online content. It includes an online database with credible information.

Harm reduction

Potential for harm reduction – everyone at the cafe/tables appeared to understand and tolerate harm reduction, some were anxious about whether schools etc. would engage with this approach. Consistency of message around harm reduction really important – but need to bear in mind appropriateness of messages for different age groups

Social media approaches

People already using social media etc so online support has less of a barrier. Apps have harm reduction information, support and help etc when and where people need it – really important.

Young people

Reaching young people – apps and online a good new method for increasing engagement. Schools – a general feeling that this information needs to go out to schools, including some credible information into primary schools

Promoting choice and offering range of support

Menu of options important – getting credible and relevant options for info and support depending on individual needs.

Online support growing both for one on one support and group support including SMART recovery – good for people who can't access services.

Appendix Six – Notes on User Involvement Discussions

Table 1

- Get families involved, not just service users
- Get families involved in consultation
- Peer advocacy and peer research
- What is the role of methadone – in harm reduction and in recovery? – service users who are/have been on methadone should be peer supporters, sharing their experiences. This will help the service user become more prepared for ORT
- Harm reduction should address stigma – emotional impact of drug user for service user and families
- Harm reduction should work with families – so they can understand more about their significant others behaviour, but also about reducing the harm impacting on families via shame, fear, worry, isolation
- SUI in harm reduction is best via an open door – use 24 needle exchanges to involve people
- Mental health and criminal justice – voices should be deliberately sought in these groups

A lot of discussion on the first table about methadone and the role of substitute prescribing – feeling that the use of methadone is no longer harm reduction, but seen as a way of 'dealing with' people regardless of whether they comply with the treatment or not.

Harm associated with drug use is widely reported in the media and this is the message most communities see first and retain – so need for positive harm reduction information to be put out so families and the public can better understand strategies/methodologies and role of harm reduction in recovery.

Table 2

- Use support groups – for service users and for families = moving forward together
- User involvement and inclusion in groups helps to 'normalise choices' – take the extremism out of addiction, eg when service users come together in a group, whether they are current users or abstinent, in the group no-one is under the influence or using negative drug talk, thereby 'normalising' attendance.
- Shouldn't be silos in harm reduction – groups should be open to current users and abstinent users – with professional support
- Set boundaries of group dynamics – abstinent and non abstinent meet together under the governance of the group purpose – is it a leisure group, eg curry night in Forth Valley, or a support group with an agenda
- See the person, enable their choices
- SU should be encouraged to drive their own recovery

- Have support in place to enable SU to be involved, reduce anxiety and vulnerability. Particularly in relation to representation, eg attending service meetings, being involved in recruitment etc
- Support needs to be matched from services to SU to maximise their engagement in activities – so mentorship, communication, coaching etc. Don't expect a SU to be autonomous and independent in a professional forum/environment. Reduce intimidation and separateness felt between workers and SUs
- Promote life stories – aim these are communities to enhance awareness and significance of harm reduction
- Involve SU and their experience to educate clinicians and change their practice, particularly around use of methadone

Table 3

- SU groups, open to everybody – abstinent or not. Some workers could attend to support the group. Have a combination of information and formal nights, eg curry nights.
- Use posters to advertise. Services should also be proactive in promoting UI
- Peer researchers role in engaging service users
- Good to have current users on the group as they bring information and perspective of what is currently happening in the drugs scene and on the streets.
- SU groups can meet with services and offer direct feedback to them – happening in Forth Valley
- Public perception of addiction and harm reduction is often from a small minority of voices and this isn't always positive. Should be greater breadth of voice being accessed and broadcast
- Voices need to be representative
- SU group running in HMP Glenochil – start SUI in prison and carry on out to community
- Training should be available for services to be able to work for SUI – how, who, when, etc
- UI gets a muddy at present – services don't know what they are wanting and how to do it.
- Stigma prevents UI – people may be anxious about coming forward
- 'Harm reduction isn't sexy anymore, but it's essential.'
- Harm reduction and recovery should be blended agendas
- Harm reduction and recovery shouldn't be mutually exclusive
- 'Ultimate harm reduction is abstinence' so is part of the journey
- There is a perceived contradiction between user involvement and the recovery movements view of the role of abstinence in UI. Not necessary
- Greater use of contingency management in harm reduction and treatment compliance.

Table 4

- User involvement needs to be creative and be more than a paper based exercise
    - Questionnaires often use complicated language, eg care commission ones
    - Questionnaires can be barriers – language, jargon, education, confidence and ability to complete
    - Use newsletters
    - Get harm reduction services users involved
- Intoxication should never be a barrier to involving a service user – look for more appropriate and creative ways of engaging current users
- Because user involvement is hard is no reason not to do it
- Ask for persons opinion ' what do you want?'
- Be person centred, involve a service user about *their* experience
- Involvement in a peer support group felt brilliant – empowered. Moving into being a representative on different groups and activities alongside workers made feel equal, valued with equal decision making
- Involving SU at the beginning, including asking their views build their own knowledge and confidence to be an active participant in treatment.
- Involvement reduces stigma
- Communication is essential – 2 way. Ensure that services include feedback to service users from any consultation or development activity.
- Service evaluations is a good way of including SUs opinions – they shouldn't be a one off
- Should be a continual review of UI – 'how can we improve SU involvement?' 'how can we be better?'
- Families should be involved in SU involvement, not just drug and alcohol users
    - Education for families and communities about different alcohol and drugs and harms
    - Involve family so they can get the context of harm reduction messages
    - Educating families about drink and drugs and harm reduction – reduce service users ability to manipulate harm reduction messages, eg 'they told me to swap vodka for beer, so that's ok', 'they told me to cut down and that's me doing well.'
    - Education for families about different drugs and alcohol related harms
- Harm reduction services are more accessible for service users – they accept the drug use as it is and therefore there is more encouragement as a service user to engage as not being told ' don't do that, you must do that'. Choice is given from the start.
    - Experience of negative impact of projects that have 'rules' which feel oppressive – if you're telling me what to do all the time, then you won't be interested in what I want to say. Harm reduction services are more embracing and less directive

Appendix Seven – Feedback

Flip chart comments quoted from participants:

Something you liked

- Chance to discuss issues which may be perceived as challenging e.g. drug consumption rooms
- Breadth of skills/experience
- Meeting folk
- Bringing people from a range of services together
- Everything
- Mix of people
- The absence of the harm reduction vs recovery debate

Something didn't like/could be improved

- Venue too small x 2
- No buffet

Something you will take away

- Broader understanding
- All the information and education
- A boarder understanding of the harm reduction method

Suggestion for future cafes

- More of the same ☺
- More of them around the country
- Sex and health education
- Larger venue
- Drugs and sex

Appendix Eight – The Talking Wall – What Does Harm Reduction Mean To You?

Whatever is required for physical and mental stability

Saving lives

Credible information enabling people to make an informed choice meeting their own needs

More action , less talking

Choice

Helping people to use substance of choice safely

Menu of options for different people and situations

Reducing deaths with widespread naloxone distribution

Offering support to people no matter what their goals are

Challenging inequalities

Making people safe

Accepting people where they are

Recovery is a spectrum

Reducing some of the risks of taking drugs for the user, and lessening the knock on effects of drugs on community etc.

Reducing harm, providing range of options, credible, relevant info and support

Harm reduction is about reducing harm for substance use. It incorporates a lot of approaches and does not preclude abstinence or

Being controversial if it helps people

No harm reduction can mean no recovery sometimes

Self respect

Harm reduction allows recovery

The right person, the right time, the right place

Offering support and advice to both stable and chaotic members of society involved in substances use

Information being more readily available

Chasing the pioneers

Being visible and available

Life saving

Taking a first step towards recovery