

Technical review of hepatitis C health promotion resources

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National Centre in HIV Social Research



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Executive summary

Introduction

The hepatitis C virus affects approximately 200,000 Australians (National Centre in HIV Epidemiology and Clinical Research [NCHECR], 2010) and to date there is no vaccine available to prevent transmission. In New South Wales, there were 3,950 new diagnoses of hepatitis C infection in 2009 (NCHECR, 2010). In all Australian states and Territories, hepatitis C disproportionately affects people who inject drugs; 90% of all new infections are attributed to unsafe injecting (NCHECR, 2006; Razali et al., 2007). Prevention interventions are therefore primarily targeted at people who inject drugs. Along with needle and syringe programs, the provision of information has been the cornerstone of the preventive hepatitis C response in Australia. Primarily, this has been in the form of educational resources aiming to increase knowledge of transmission.

Common educational approaches to blood-borne virus prevention among people who inject drugs include peer education, one-on-one health promotion and distribution of print and audio-visual educational materials. The effectiveness of these interventions in preventing hepatitis C transmission, or producing behaviour change, is difficult to evaluate and few attempts have been made to do so. However, social research has highlighted that the ability of individuals to adopt safer injecting practices is mediated by structural, social and environmental, as well as personal factors, which call attention to what may be important considerations for framing hepatitis C prevention messages.

In NSW, and Australia more broadly, print hepatitis C prevention education materials are most commonly produced by government-funded community organisations and government departments, financed by core or one-off funding streams. Resources are produced within a social, legal and political context which may serve to inhibit content; to some extent, producers are limited by what may be acceptable to an audience wider than the target group, and the perceived moral implications of providing direction for the safest preparation and consumption of illicit drugs.

Aims

The National Centre in HIV Social Research at the University of New South Wales was funded by NSW Health to undertake a review of existing print-based hepatitis C prevention education resources aimed at people who inject. The aims of this study were to:

- Establish what resources and messages have been produced to date
- Catalogue the types of messages identified
- Catalogue the message delivery format
- Examine any evaluations conducted of resources or messages
- Drawing on those evaluation findings, to identify successful resources and messages to be replicated or built on and to document gaps in existing approaches
- Make recommendations for message content, presentation and targeting strategies

Methods

Existing hepatitis C educational print resources were collected from Australian organisations working with people affected by, or at risk of, hepatitis C infection. The materials were catalogued and analysed using a reference framework which was developed in conjunction with a project advisory group and informed by the existing social research literature. The framework specified the following broad areas of analysis: production information, design/presentation, content (e.g., what and how key messages are conveyed, language, currency of information, framing of injectors, hepatitis C etc), audience inclusion/exclusion, and any assumptions or absences.

Results

A total of 159 resources, produced between 1991 and 2010, were catalogued and analysed. One third of the materials were specifically aimed at people who inject and focused on hepatitis C

prevention. Two-thirds of the resources were targeted at people who inject but may or may not have included hepatitis C prevention as their primary focus. The targeting of resources was apparent by factors such as language, imagery, the extent of emphasis on drug injecting, or the resource title or producer. The key findings are summarised below.

- Hepatitis C was variously characterised as active, aggressive, elusive, cunning or stealthy, and/or tough and hardy. By endowing the virus with such qualities, the notion of something to be feared and avoided was constructed and reinforced.
- Key hepatitis C prevention messages aimed at people who inject centred on instructing them not to share injecting equipment, and to avoid blood contact or blood transference from one person to another. In early materials, instructions not to share injecting equipment initially specified only needles/syringes or 'fits'. Some later materials start to also identify ancillary injecting equipment (e.g., spoons, swabs etc) and this became the norm. However 'sharing' equipment was rarely explained, and at times it was conflated or lumped with re-using (one's own) equipment, creating potential for confusion.
- The concept of being 'blood aware' featured heavily in materials. However, being blood aware in relation to the injecting procedure was not always well explained. The few materials that did describe specific scenarios where blood could be transferred from one person to another implicitly acknowledged the often social nature of drug consumption.
- Responsibility for prevention of hepatitis C transmission was almost always framed as individual. This framing was achieved through directives which explicitly or implicitly addressed the intended reader (people who inject, people with hepatitis C). Individual responsibility was also sometimes invoked to protect others from infection (e.g., not allowing others to use [your] used injecting equipment).
- Prevention advice was rarely informed by consideration of the social and environmental factors which may impact on an individual's ability to follow the safer injecting instructions. The few that do so primarily focussed on access to injecting equipment or a clean environment.
- Almost all materials assumed that the target group had sufficient access to the resources required to adopt the safer injecting practices advised.
- As expected, hepatitis C information and prevention messages have evolved over time, reflecting changing knowledge since the identification of the virus. Notwithstanding this, insufficient attention was paid to the possibility of hepatitis C reinfection and superinfection.
- Among those materials that explicitly addressed hepatitis C testing, different testing types and the meaning of results were not always well explained. For example, a positive antibody test result was sometimes presented as conclusive evidence of current infection.
- Medical and other jargon was frequently employed in describing hepatitis C symptoms, transmission and treatment. While the more comprehensive resources included a glossary of terms, many used such terminology without explanation or description.
- A4 size fold-out pamphlets and A5 booklets were the most common formats in this sample but materials produced in later years utilised a wider variety of formats including wallet cards, postcards, bookmarks, comics etc. Along with innovations in presentation, the use of colour became more pronounced over time, probably reflecting improved technology and access to desktop publishing by community organisations. Despite this, the use of imagery to represent injecting drug use did not vary – it was infrequently used. This probably reflected the limitations generated by needing to conform to a degree of social acceptability in the production of resources.
- Some of the materials still in circulation at the time of data collection included information that was out of date. While some resources included disclaimers and advice to check that information was still current, the inclusion of a review or expiry date was rare.

Recommendations

Based on the research findings, the following recommendations are made for the design and distribution of hepatitis C educational materials aimed at people who inject drugs. These relate to all aspects of the conceptualisation, development, design, dissemination and evaluation of hepatitis C prevention resources. They also include the ways in which the target audience is involved in aspects of this process.

Responsibilities, limitations and access

1. Acknowledge that responsibility for prevention is shared

Hepatitis C prevention messages should seek to avoid blame, which can reinscribe stereotypes and stigma. Consideration should be given to balancing individual responsibility and shared responsibility for prevention. Individual responsibility for hepatitis C prevention needs to be contextualised against the wider responsibilities of organisations, governments and society. This can be done, for example, by outlining the measures governments are taking to address hepatitis C prevention, and by framing people who inject as partners in the wider response.

2. Consider the restrictions of the local environment (including injecting environment and supply of equipment)

Prevention advice should be realistically achievable by the target group. For example, local factors, such as the availability of needles/syringes or sterile water, influence individual ability to undertake the safer injecting practices promoted. Incorporating suggestions for practice which are unachievable because of local context issues can reduce the credibility and usefulness of the health promotion resource or activity.

Message targeting

3. Repackage for specific target groups

Messages should be tailored with consideration of the diversity of people who inject, taking into account that many may not identify as part of a community of injectors or drug takers. This may mean regularly repackaging information based on the interests of the specific target group. Tailoring messages based on epidemiological risk categories (for example, people who inject in public, people with unstable housing) can be problematic as these categories are not easily identifiable in reality and can include diverse and overlapping populations. Careful planning is needed in the development phase to ensure that messages are appropriately packaged and targeted to avoid alienating or stigmatising groups or practices.

4. Contextualise hepatitis C prevention within the diversity of injectors' experiences

Didactic messages can be perceived as patronising, and traditional prevention advice and methods may be seen as irrelevant by target groups. If packaged with new useful information and other resources, prevention advice can have fresh impact. The principle is to avoid foregrounding potentially bland or unappealing messages by contextualising hepatitis C prevention within people's lives more generally. Going beyond traditional print-only educational resources and campaigning to create innovative ways of distributing information could aid in attracting renewed interest from the target group. The relevance of standard prevention messages can be increased by including other useful materials or messages. For example, one resource (not included in this review of print materials) consisted of a toiletries bag and toiletries, which also included hepatitis C prevention information. This may also be a way to interest new injectors who may not relate to traditional methods of education. Other messages shown in the social research literature to be supportive of safer injecting practices include those relating to health and social issues beyond hepatitis C itself. For instance, it is important to recognise that some people who inject drugs consider track marks, their visibility, and the stigma they can attract, a more significant issue than hepatitis C.

Likewise, some readers may be more concerned about building and maintaining healthy and workable social relationships whilst managing drug use, or managing the financial aspects of drug use to avoid withdrawal symptoms. Others again may be most interested in promoting hygienic practice in injecting (to prevent 'dirty hits' and to maintain hygienic practice and general health).

Digital communication mechanisms may also offer novel ways of accessing new and young injectors and provide new possibilities for the tailoring, packaging and delivering of information.

5. Address injecting in groups

Further attention could be paid to group injecting situations: social conventions related to injecting can impact on individual ability to enact safer injecting practices. Within groups, individuals may have specific roles as determined by their relationships with others present, especially as this relates to gender and intimate relationships. Also, the injecting setting may influence who has the ability to shape practice (e.g., when injecting occurs at an individual's home).

6. Ensure input from a number of sources, particularly the target group, in resource development

Peer involvement is essential at every stage of message development. All messages developed should have input from a number of sources balancing best available information and insights from the target group with knowledge drawn from social research in hepatitis C prevention and the broader health communication literature. This balance will limit the risk of reproducing stereotypes about people who inject drugs and their practices.

Approach

7. Policy support for future resource development

Policy should support conditions that not only facilitate the timely and accurate design and delivery of messages, but also 'safer injecting environments' themselves. For example, policy should not hinder a community response to emerging health issues by censoring messages considered politically unpalatable. Further, there is a need for NSW Health to undertake a program of communication about policy and processes concerning resource development, distribution and approval. This will enhance stakeholder understanding of what is involved in the approval process, and minimise the potential for misconceptions about constraints that may lead to diminished breadth or innovativeness in resources.

8. Currency and timeliness of information

Materials in distribution should always be up to date. Knowledge about hepatitis C and treatment changes

rapidly. All resources should therefore include a date of publication and a recommendation to review by a set future date. A supporting strategy involving the recall of out-of-date materials should also be built into resource design and funding, to minimise the continued circulation of materials that are no longer accurate. These publication and review dates should be clearly written on the resource, so they are visible to readers. Further 'caveats' could also be embedded in the text, making clear that the information is subject to change and update, for example, expressions such as 'based on what we currently know...' could be used.

9. Use of plain language and avoiding jargon

Prevention messages and transmission descriptions should not presume that readers understand jargonistic terms and phrases (e.g. 'blood-to-blood contact', 'acute'/'chronic' hepatitis C infection). They may be a source of confusion as they do not provide adequate descriptions. Simple, non-technical language can help to carry a message clearly and without confusion.

10. Use of conditional rather than absolute language to promote mindful practice

Absolute language limits alternative ways of interpreting and applying the information being presented. Resources should aim to make greater use of conditional language; this means changing directives such as 'never' and 'always' to words such as 'perhaps', 'possibly', 'typically' and 'one way of...'. For example, the following sentence promotes thoughtful engagement: 'it is important to consider whether

any pieces of equipment might have been used by anyone else. Could the water you have been using for mixing up have been used by anyone else? If you are unsure, and there is more water available, it is better to get water that you know is clean and hasn't been used by anyone else'.

11. Ensure an evaluation strategy is in place

Evaluation of resources should be built in from the outset of resource design. The development of strategies to assess the distribution and uptake of the materials, as well as structured feedback on their perceived value and their use should be part of the development process.

12. Resources should be focus tested with members of the target audience

In that health promotion messages can themselves reproduce stereotypes and stigma, it is important to recognise that they can do worse than be ineffective. Where it involves members of the target audience as key collaborators, focus testing of resources helps to identify ways in which targeted readers interpret messages. Ideally, focus-testing is best facilitated by an appropriately trained member of the target group.

While focus testing is essential, it does not in itself insure materials against ineffectiveness or the introduction of damaging stereotypes. As with all other publicly funded publications, hepatitis C health promotion literature has a responsibility to avoid sexist, racist and other derogatory representations, even where those representations circulate within the target readership.

Introduction

The hepatitis C virus affects approximately 200,000 Australians (National Centre in HIV Epidemiology and Clinical Research [NCHECR], 2010) and to date there is no vaccine available to prevent transmission. While improvements in treatment have been achieved over the last decade, prevention remains the primary focus of Australian hepatitis C policy, in the context of around 10,000 new infections each year (Razali et al., 2009).

In New South Wales, there were 3,950 new diagnoses of hepatitis C in 2009 (NCHECR, 2010). In all States and Territories, hepatitis C disproportionately affects people who inject drugs; 90% of all new infections are attributed to unsafe injecting (NCHECR, 2006; Razali et al., 2007). There are difficulties in accurately assessing the prevalence and incidence of hepatitis C among people who inject since the population of injectors is largely unknown, however research and surveillance with community and needle and syringe program samples has variously estimated a national prevalence of between fifty and sixty percent. Fifty-three percent of NSW participants in the Australian Needle and Syringe Program Survey tested positive for hepatitis C antibodies in 2010; this prevalence has fluctuated from as high as 84% since surveillance began in 1995 (Kirby Institute, 2010). Of all the States and Territories NSW has among the highest prevalences of hepatitis C among people who inject.

As injecting drug use is the major mode of new infections, prevention interventions are primarily targeted at people who inject drugs. Along with needle and syringe programs, the provision of information has been the cornerstone of the preventive hepatitis C response in Australia. Primarily, this has been in the form of educational resources aiming to increase knowledge of transmission prevention, both in the general community but particularly among people at risk. Indeed 64% of a sample of 336 Australian people who inject, reported their most common source of information about hepatitis C and safe injecting practices was pamphlets, followed by needle and syringe programs – 63%, friends – 47%, and doctors/nurses – 34% (Treloar and Abelson, 2005). The current limited hepatitis C prevention activity reflects the insufficient funding sources available for hepatitis C education, and the limitations of workforce capacity (Perfrement, 2003).

Information provision, or health communication, is conducted on the basis that people will change risk behaviours when armed with the information required to protect their health. Examples of such a public health response can be seen in the development of anti-smoking and HIV prevention campaigns in the past few decades. However, information provision approaches are 'limited...by the paradigm of the 'expert' professional making decisions about what information is presented.' (Perfrement, 2003, p21). Adult learning principles were

incorporated into practice during the 1980's which improved involvement of target groups, but often failed to account for many people's lack of control over their lives, and their lack of resources to take action to improve their health outcomes (Perfrement, 2003).

In the hepatitis C field, consumer (people who inject drugs) involvement and self-determination has been supported by the advent of drug user advocacy groups which provide both a voice for the community most affected by new hepatitis C infections, and an avenue of participation in the development of policy and practice relating to prevention. Drug user activist networks emerged during the 1980's, bringing sterile needle and syringe provision amongst peers to prevent HIV infection. This demonstrated both a desire to protect health and the potential for community mobilising among a population often considered lacking in organisation and self-worth.

The prevention of hepatitis C transmission among people who inject requires not only the knowledge (and desire) to prevent transmission, but also the resources and 'enabling environments' (Rhodes et al., 2005) to do so. This entails not only improving knowledge, but also providing the means, including sterile injecting equipment and safer injecting environments, but also developing and implementing supportive social and public health policies.

Theoretical frameworks

In the field of Health Promotion, theories/models of behaviour change predominating in the past half century have relied on motivating the 'rational individual' in achieving health-positive behaviour change. Health communication strategies assume a decision-making process of rational individuals who follow a linear path from awareness to attitude to action (Airhihenbuwa and Obregon, 2000). A brief outline of the major behaviour change theories/models and communication models and strategies is provided below.

Behaviour change theories/models

- Health-belief model: an individual's motivation to change behaviour is predicated on their perceived susceptibility to the disease, perceived severity of the disease, perceived benefit of action, and perceived barriers to action.
- Theory of reasoned action and planned behaviour: 'intention to act' is considered the most immediate determinant of an individual's behaviour; this intention is directly influenced by attitudes towards behaviour, subjective norms and perceived behavioural control.
- Social-cognitive theory: individual behaviour is the result of the interaction of individual cognition, behaviour and environment. These determinants may act sequentially or simultaneously.

- Transtheoretical stages of change model: behaviour change is a process involving stages of change, from precontemplation to contemplation, preparation, action, and maintenance.

Health communication models and strategies

- Information processing model: individuals actively process information by a cognitive process which includes the encoding, storage and retrieval of information.
- Message effects theories: examine how features, formats and content of messages produce changes in knowledge, attitudes and behaviours.
- Communication-persuasion model: proposes using five factors (source, message, channel, receiver and destination) at the input stage of designing a campaign, and then assess whether these inputs are likely to achieve the desired outputs to mediate behavioural change. Output factors include: tuning in, attending, liking, comprehending, generating, acquiring, agreeing, storing, retrieval, decision, action, post-action, converting.
- Social marketing: applies commercial marketing principles and techniques to influence target audience behaviours. Key principles include being: consumer orientated, focus on behaviour, market perspective, audience segmentation, marketing mix (product, price, place, promotion), and positioning.

Criticisms of behaviour change theories/models include the inherent assumption of a rational decision-maker, the emphasis on individuals and lack of recognition of structural influences, and the failure to recognise the role of emotion in decision-making (Airhihenbuwa and Obregon, 2000). Considering existing theoretical frameworks of behaviour change inadequate for non-Western cultures, a decade ago UNAIDS commissioned a working group to develop a new framework for HIV health communication which focuses on contexts that influence individual behaviours: government policy, socioeconomic status, culture, gender relations and spirituality (Airhihenbuwa et al., 2000).

Health education and communication

Educational interventions aimed at improving knowledge in order to motivate behaviour change can take many forms. Common approaches in the area of blood-borne virus (including HIV and hepatitis C) prevention among people who inject include peer education, one-on-one health promotion by needle and syringe program workers and AOD service workers, group workshops – delivered for example at needle and syringe programs or in prisons, and the distribution of print and audio-visual educational materials. A report of a 2009 review of educational interventions targeted at people who inject and people at risk of initiating injecting identified the following barriers to delivery: the heterogeneity of people who inject, difficulties in reaching people before injecting behaviours are established, professionals' incorrect assumptions about the knowledge of the target group, literacy difficulties, that knowledge of hepatitis C risk does not necessarily deter injecting, and people who inject's lack of recognition of unconscious habits (Griesbach and Taylor, 2009).

Factors that contribute to the effectiveness of educational interventions were also identified. The authors conclude that good educational interventions require minimal literacy, are interactive, are supported with audio-visual resources, use appropriate language, are relevant and tailored specifically to the target group, allow people to learn at their own pace, give people opportunities to practice new behaviours, are delivered by people with credibility and are delivered regularly and consistently (Griesbach and Taylor, 2009). These findings support assertions by Petraglia (2009, p. 177) that in order for health communication to be well-received by the target group it must be considered authentic by them.

Authenticity, Petraglia states, is "...not just perceived relevance but a felt relevance that pulls information out of the background and to the fore. Authenticity enables individuals to understand, emotionally as well as cognitively, how information can relate to their everyday existence" (p. 177).

According to Petraglia's thesis, authenticity is achieved using both narrative and dialogue. Without being authentic in the perspective of the target group, messages about disease and exhortations to change risky behaviour can become 'white noise' (Petraglia, 2009). When designing health promotion messages, the goal of the message, the target audience, the medium used and the personal relevance of the messages should all be considered, as they affect aspects of message processing (Lang, 2006).

Insights from social research

While there is much in the literature about HIV prevention interventions there are few published studies which have examined the effectiveness of hepatitis C educational interventions, and fewer assessing print materials. However, social research has highlighted some of the issues important for framing hepatitis C prevention strategies. The ability of people who inject to adopt safer injecting practices is influenced by structural, social and environmental factors. The risk of arrest, stigmatisation, drug withdrawal, breeches of confidentiality, and violence may play a part in decision-making and compete with the priority of hepatitis C prevention (Grund et al., 1996; Rhodes, 2002; Cooper et al., 2005; Small et al., 2007; Rhodes and Treloar, 2008; Simmonds and Coomber, 2009).

Social research identifies: that IDU describe varying levels of knowledge about hepatitis C, perceive hepatitis C through a HIV 'lens' and see hepatitis C as ubiquitous (i.e. everyone has it, therefore it's difficult to avoid), a sense of generational differences in cultures of risk (Rhodes et al., 2004); social and cultural (compared to epidemiological) meanings of equipment 'sharing' (Maher, 2002; Carruthers, 2003; Rhodes et al., 2004); contested notions of blood (Treloar and Fraser, 2004) and blood awareness (Treloar, 2005); the importance of models of habitual behaviour (Treloar, 2005; Treloar et al., 2008); and moral taxonomies (user, addict, junkie) relating to, among other things, pervasive notions of being a clean and virtuous user (Boeri, 2004).

Educational interventions require careful planning in order to: avoid reinscribing stigma and blame, disrupt the binary logic of being 'clean' or 'contaminated' (Fraser and Treloar, 2006), consider the impact of responsabilising the individual for the onus of prevention and creating an unrealistic burden of hygiene (Butt, 2002; Dodds, 2002;

Davis and Rhodes, 2004; Fraser, 2004), move towards a consideration of drug use settings, structural influences and the social nature of drug use (Rhodes, 2002; Rhodes et al., 2005; Rhodes and Treloar, 2008; Dwyer et al., 2010), acknowledge the heterogeneity of people who inject (Ellard, 2007), consider the role of pleasure and emotion in decision-making (Airhihenbuwa and Obregon, 2000; Dwyer, 2008; Moore, 2008), and acknowledge unconscious habits in injecting practice (Treloar, 2005).

Context of educational resource production

In New South Wales, and Australia more broadly, hepatitis C prevention education materials are most commonly produced by government-funded community organisations, and government departments, which operate to advocate for and/or improve the health of affected or at-risk communities. Examples include state-based Hepatitis Councils, drug user organisations, and government health departments. The development of targeted educational resources is most commonly financed via government funding streams (either through core or one-off funding) and as such is required to meet prescribed specifications under departmental guidelines. This can operate both positively and negatively. For example, such conditions may require focus-testing and built-in evaluation plans prior to release which aim to ensure acceptability to, and impact on, the target group. However, these sometimes lengthy processes may also serve to delay the release of resources, which can affect the timeliness of a response to a newly identified or emerging issue.

Resources are produced within a social, legal and political context which can place considerable constraints on their content including imagery, messages and language. To some extent, producers of materials are limited by what may be acceptable to an audience wider than that which is intended (the target group). There are examples of occasions where resources have ended up in the hands of an unintended audience and caused public consternation due to the perceived graphical nature of the content and lack of understanding of its public health relevance. Further, producers may be restricted by the perceived moral implications of providing considerable detail in directing the (safest) preparation and consumption of illicit drugs.

Aims

The National Centre in HIV Social Research at The University of New South Wales was funded by NSW Health to undertake a review of existing hepatitis C prevention education resources aimed at people who inject.

In the context of materials produced to convey safer injecting advice to prevent the transmission of hepatitis C, the aims of this study were to:

- Establish what resources and messages have been produced to date
- Catalogue the types of messages identified
- Catalogue the message delivery format
- Examine any evaluations conducted of resources or messages
- Drawing on those evaluation findings, to identify successful resources and messages to be replicated or built on and to document gaps in existing approaches
- Make recommendations for message content, presentation and targeting strategies

Methods

Data collection

Hepatitis C educational print resources were collected from Australian organisations working with people affected by, or at risk of, hepatitis C infection. This included for example, state-based hepatitis organisations, state-based drug-user advocacy groups ('drug user organisations'), health services and other community-based advocacy and health organisations. The initial collection of resources occurred between November 2008 and October 2009, and a follow-up collection – limited to NSW-based and National organisations only - was conducted during August 2010 in order to ensure materials produced since October 2009 were included in this analysis.

Initially, a research assistant requested copies of all materials the organisations had ever produced via a letter which detailed the aims of the research project. Materials were also collected from online sources and by visiting organisations in person wherever possible. The follow-up collection involved a research assistant contacting National and NSW-based organisations via telephone to request copies of any recently produced (October 2009 – August 2010) materials. The research assistant also requested copies of any reports evaluating any materials the organisation had produced or used (not time limited).

Materials were included for this review if they featured a section on hepatitis C transmission/prevention and injecting. Collected materials were excluded if they were centred on another health issue and did not address hepatitis C transmission in the context of injecting. For example, some of the collected materials focused on things such as nutrition and living with hepatitis C, pregnancy, treatment options etc.

Data analysis

A framework of analysis was developed in conjunction with an Advisory Group consisting of academics, a health promotion consultant, NSW Health and representatives of consumer organisations. A half-day workshop was held to brainstorm the areas of interest and a framework subsequently drafted and approved by the Advisory Group. The framework was also informed by the existing social research literature.

The framework directed the following broad areas of analysis:

- General information (including producer organisation, funder, endorsements, year of production, revision number).
- Design/presentation (including format – e.g. pamphlet, wallet card etc, use of images, graphics, colour, size, amount/density of text, effects of use of images and presentation etc).
- Content (including key messages, how messages are conveyed, alignment with current knowledge, language utilised, framing of responsibility for prevention, attention to the injecting environment, etc).
- Target Groups (tailoring to specific target groups and how this is achieved, inclusion/exclusion of groups, reinforcement/challenging of stereotypes etc).
- Other (assumptions made, absences, presence of the user's voice).

The full analysis framework utilised is included in Appendix 1.

The materials were catalogued and reviewed according to the agreed framework. A sub-set of the Advisory Group held a second half-day workshop to discuss and interpret the findings and draft recommendations. A draft report was circulated among the Advisory Group for feedback and then finalised with the NSW Department of Health.

Analysis of materials

A total of 218 materials were collected in the first round of data collection, and a further 11 in the second round. Seven evaluation reports were collected, however only four of these focussed exclusively on the assessment of print materials, the other three were evaluation reports of comprehensive hepatitis C education programs which included print resources as part of a suite of activities. A summary of the evaluations is provided in Appendix 2.

Of the 229 resources collected (218+11), a total of 159 were catalogued and analysed for this study. Materials which did not include a component of hepatitis C transmission advice/education relating to injecting drug use were excluded ($n=70$), in keeping with the aims of this study. Excluded materials ranged from those addressing health, social and lifestyle

aspects relating to living with hepatitis C to treatment options, managing disclosure and discrimination, and materials which were aimed at healthcare professionals.

The reviewed materials were produced between 1991 and 2010, the majority (124/159) having been produced in the latter decade (2000-2010). Twelve resources were not able to be dated. Most (108/159) were in pamphlet or booklet form, and most (107/159) exclusively addressed hepatitis C and not other blood-borne viruses. Forty percent (64/159) were aimed at people who inject, and 35% (56/159) were primarily focussed on hepatitis C prevention among people who inject (Table 1).

The remainder of this section presents the key findings from the review of the print educational materials.

Table 1: Summary of materials reviewed

NB: Percentages are rounded.

*Does not include those aimed at general community.

Materials may appear in more than one group (e.g. prisoners and low literacy and people who inject).

	<i>n</i>	%
Total materials reviewed	159	100
People who inject and hepatitis C prevention specific	56	35
Producer organisation type		
Hepatitis organisation	69	43
Drug user group	35	22
Alcohol and other drug service/needle and syringe program	15	9
Government department	14	9
Other health/community advocacy organisation	16	10
Aboriginal health service	6	4
Community/Area Health Service	3	2
Unknown	1	<1
Format		
Booklet	57	36
Pamphlet	51	32
Postcard	13	8
Factsheet	12	7
Poster	9	6
Fold-out wallet card	7	5
Wallet card	6	4
Other	4	2
Year produced		
1991	1	<1
1992	1	<1
1993	0	0
1994	1	<1
1995	2	1
1996	4	<3
1997	3	2
1998	5	3
1999	5	3
2000	12	8
2001	6	4
2002	7	4
2003	20	13
2004	12	8
2005	8	5
2006	10	6
2007	12	8
2008	19	12
2009	16	10
2010	2	1
Unknown	12	8
Address:		
hepatitis C only	107	67
Blood-borne viruses generally	29	18
Hepatitis viruses	19	12
Other (e.g. no blood-borne virus mentioned but safer injecting advice included)	4	3
Target groups*:		
People who inject (general)	64	40
Steroid users	4	3
Amphetamine users	1	<1
Indigenous	11	7
Young people	6	4
Prisoners	3	2
Women	4	3
People with hepatitis C	32	20
Low literacy	3	2
Culturally/linguistically diverse (English language only)	4	3
Other inclusions		
Families	13	8
Couples: sexual	54	34
Couples: injecting	12	8
Groups (including couples, families, friends)	63	40
Other drug-use harms addressed (in materials aimed at people who inject, n=64)		
Overdose	8	13
Non-viral (bacterial) infections, dirty hits, septicaemia, abscesses etc	13	20
Drugs and their effects	10	16
Social, financial, legal	23	36

Overview of sample

Materials could be divided into two loose categories; (1) those which were generic hepatitis C information resources, and that cover – in brief, or in detail – basic hepatitis C information including epidemiology, transmission, symptoms, living with hepatitis C, possible infection outcomes, prevention advice, testing, and treatments, and (2) those which addressed a specific aspect of hepatitis C, such as transmission risks and prevention. The former were more likely to be aimed at the general community and the latter were more commonly targeted at people who inject and specific risk sub-groups (e.g. young people, prisoners, Aboriginal people). The targeting of resources was apparent by factors such as language (e.g. street slang), imagery (graphical representations of drug preparation), and the extent of emphasis on drug use and injecting, or simply the title of the resource (e.g. ‘Women and Hep C’) or who the resource was produced by (e.g. drug user organisation).

Hepatitis C was most commonly dealt with separately to other blood-borne viruses; only one-fifth addressed blood-borne viruses generally, and less than one-sixth dealt with a number of hepatitis viruses (most commonly hepatitis A, B and C together). Some resources, which primarily focussed on safer injecting advice targeted specifically at people who inject, addressed blood-borne viruses in general, as part of a general exhortation to avoid blood transference during the drugs preparation and injecting process. Resources which were created during the 1990’s were predominantly general information resources, fitting into the first category described above. Only limited prevention advice relating to injecting was included (e.g. ‘People with hepatitis C should not... share needles/syringes’ [original emphasis] (‘Hepatitis C Factsheet’, NSW Health, 1992)). As knowledge about hepatitis C developed over time, messages became more targeted, detailed and specific to one particular area or risk group, reflecting the emerging epidemiology.

The manner in which prevention messages were targeted and conveyed also became more sophisticated and creative over time. Materials produced during the later years of the 2000’s became more colourful, eye-catching and creative, departing from the standard A4 letter-fold pamphlet or small booklet. Specific targeting of population groups became more apparent, either implicitly through the use of slang such as ‘fit’ for needles/syringes, or explicitly through the use of inclusive language such as ‘we’, although the latter was rare.

Content

Framing of hepatitis C

Hepatitis C was usually characterised as ‘active’ in that it was described as ‘causing’ inflammation of the liver. Sometimes it was framed more aggressively, for example ‘...virus enters your body it seeks out its particular host cells. It then enters the cell, hijacks its functions and set it to work as a virus-making factory..’ (‘Testing and Diagnosis: Hep C & HIV’, AIVL, 2002) and ‘HIV is not the only blood borne virus that threatens injecting drug users’ [emphasis added] (‘Using Tips’, Inner South Community Health Service, Safer Using Series 2000). At other times hepatitis C was framed passively, where blood is constructed as the infectious agent to be avoided (e.g. ‘With hepatitis C it is important to avoid doing things that may lead to infected blood entering the bloodstream and be careful when around blood.’ (‘Hepatitis’, Multicultural Health and Support Service, 2008) or ‘Every drop of blood from someone infected with hep C will contain the virus’ (‘Hepatitis C: Information for all Australians’, Commonwealth Department of Health and Ageing, 1998)).

Hepatitis C was also frequently characterised as elusive (e.g. ‘Microscopic amounts of blood too small to see can transmit hep C...’ (‘A Guide to Safer Injecting’, AIVL, 2008)), or cunning and stealthy (e.g. ‘There are many different strains of hep C about...It’s very easy to get reinfected with another strain. Don’t let your guard down!’ (‘Stay Blood Aware’, Drug & Alcohol Services Council South Australia, 2003), and ‘[hepatitis C] is a crafty little bastard as he cannot actually be seen.’ (‘Via Us: in the vein’, VIVAIDS, 2001). It was also described as tough and hardy (e.g. ‘[hepatitis C] can live outside the body for days (even weeks).’ (‘Being Aware of Blood’, The Hep C Review Harm Minimisation Poster Series, Hepatitis C Council of NSW, 2004). One document humorously sets up a fictional warfare scenario describing a military battle between ‘Jabba the Hep’ (hepatitis C virus), antibodies, hep C carrying infantry, and the host (Shep, the protagonist in the narrative resource). It describes the mission of the platoon to invade the host, avoid destruction by antibodies and set up base camp in the liver (‘Via Us: in the vein’, VIVAIDS, 2001). By endowing the virus with qualities such as being elusive, tough and hardy etc, the notion of something to be feared and avoided is constructed and reinforced.

In a number of cases Hep C was endowed with human-like qualities (anthropomorphised). For example, ‘Following infection, the viruses (A, B or C) behave differently’ (‘The ABC of Hepatitis’, Victorian Government Department of

Health and Community Services, 1995). This description suggests the virus has rational thought, since behaviour is usually considered rational or irrational, or at least a result of contemplation. The comic 'What is hep C' (Streetwise Communications, 2004) depicts the hepatitis C virus, portrayed as cartoon people, inside a syringe and about to be injected into a vein, charging towards the bloodstream with determination and intent.

Hepatitis C transmission

Materials commonly had 'transmission' and 'prevention' as separate sections. In the transmission sections, possible routes of infection are described, such as pre-1990 blood transfusions, unsterile medical and dental procedures and sharing drug injecting equipment. Hepatitis C transmission was commonly described as occurring as a result of 'blood to blood contact'. This phrase started to be used in the late 1990's and featured heavily over time. A description of what this actually means appeared in one early resource ('Hepatitis C', Kavanah and Holmes, 1994), but did not become common until 2000, when some materials started describing further detail of what 'blood to blood contact' entails (e.g. 'Hepatitis C is transmitted through blood to blood contact, this means when blood from somebody with the virus enters the bloodstream of someone else' ('The Little Book of Hep C', Northern Sydney Health Hepatitis C Service Network, 2002)). Versions of this explanation, with only slight alteration were reproduced repeatedly over time. In a few materials, the explanation of potential for transmission lacked clarity. For example, one factsheet states 'People who inject drugs should not let their blood come into contact with anyone else's, not let anyone else's blood come into contact with theirs' ('Disposing of Fits Factsheet', Hepatitis C Council NSW, 2000). This description fails to identify the need for (infected) blood to enter another person's bloodstream; blood may come into contact exogenous to the individual and as such not pose any transmission risk.

Key prevention messages

Key prevention messages aimed at people who inject centred around instructing them not to share injecting equipment and avoiding blood contact, or blood transference from one person to another. Typical examples include:

'Don't share injecting equipment' ('Hepatitis: A guide for young people', ACT Hepatitis C Council, 2007).

'The safest thing is NOT to use injecting drugs but if you do - NEVER share injecting equipment such as: spoons, tourniquet, water, needles and syringes.' (original emphasis) ('Hepatitis C', Victorian Aboriginal Community Controlled Health Organisation, undated).

'Never share injecting equipment! Use a new fit for every hit!' ('What is hep C?', Streetwise Communications, 2004).

'A quick hit, a drop of blood, a lifetime of hep C. Don't share a bloody thing...Be blood aware, don't share. Hep C is everywhere.' ('Don't share a bloody thing', Hepatitis C Council QLD, undated).

'Stop hep C spreading. Be blood aware' ('Yarnin up hep C: Sharing information, not sickness', Relationships Australia SA, 2003).

'Do not share any injecting equipment. Avoid blood-to-blood contact' ('Hepatitis A? B? C?', Hepatitis C Council QLD, 2003).

'When preparing and injecting drugs, be blood aware, avoid contact with blood' ('Hepatitis C & Injecting Drug Use', Hepatitis C Council QLD, 2002).

'Wash your hands before and after injecting' ('Hepatitis C: The Facts', Victorian Government Department of Human Services, 1996).

'Wash your hands before and after injecting someone else' ('A Fistful of Soap', AIVL, 2008).

Sharing injecting equipment

Instruction to not share (injecting equipment) initially specified only needles/syringes or 'fits'. For example, 'People with hepatitis C should not-share needles/syringes' ('Hepatitis C', NSW Department of Health, 1992). Later materials start to also identify ancillary injecting equipment (including spoons, swabs, filters, water and tourniquets) and this became the norm. However 'sharing' equipment was rarely explained, and at times it was conflated or lumped with re-using equipment, creating a potential for confusion. For example, 'To reduce the risk of transmission, it is (therefore) important that people who inject drugs do not share or reuse needles...even when no blood is visible' ('Impact: Hepatitis C information', Hepatitis C Council Vic, 2003). Only a couple of resources describing detail on safer injecting practices made the distinction that it is preferable for people who inject to re-use their own fit than someone else's.

'FROM BEST TO WORST: (1) Use new injecting equipment every time including new fits, sterile water, new swabs, a clean spoon, tourniquet, filter and a clean injecting space and clean hands. If you can't get a new fit - (2) Choose to wait until you can get a new fit. (3) Try using your drugs another way e.g. smoking, snorting, swallowing or stuffing (up ya bum). (4) Clean a fit that only you have used before. (5) As a last resort... clean a fit that someone else has used. ('When there's no other way: A guide to cleaning fits', AIVL, 2003).

Blood awareness

In the collected sample of materials, the concept of 'being blood aware' first emerged in 1998 and was utilised heavily after that, particularly in materials aimed specifically at people who inject. However 'blood awareness' in relation to the injecting procedure wasn't always well explained. For example, one resource features the directive 'Be blood aware—avoid blood to blood contact' ('Hepatitis C: Basic information', 'Hepatitis C Council QLD, 2000'), with the only additional explanatory information included being the exhortation to not share any injecting equipment and be aware of safer injecting practices. A few resources give an explanation of blood awareness and/or identify specific steps in the preparation and injecting process during which people who inject should be alert to the potential for blood (presence and/or transference).

'Always be blood aware!!! Being blood aware means being alert to what is happening before, during & after you inject. If you think blood, yours or someone else's, has contaminated the injecting space or equipment you should replace any sterile equipment, re-clean any other things that may have been contaminated, and re-wash your hands before proceeding.' ('Hep C not 4 me: a guide 2 staying safe', AIVL, undated, p6)

'Small amounts of blood on your hands could end up on someone else's hands if they touch anything you have touched or on their arm if you help them inject. You should wash your hands... If you continue to inject you will need to become 'blood aware'. You need to consider the various ways blood and the virus can be transferred from one person to the next...Any injecting equipment that is reused, handled or passed to another person is potentially infectious.' ('Contact: Hepatitis C diagnosis booklet', Hepatitis C Council QLD, 1998)

These materials acknowledge the often social nature of drug consumption. In the context of avoiding blood contact and transfer between people, other protective strategies were sometimes proffered in consideration of injecting in groups:

'No matter how well it has been cleaned, never let your used equipment or anyone else's come into contact with a group mix. Unless new sterile fits are used to mix and divide up, each person must have all their own equipment' ('Safer Injecting', AIVL, 2003)

'...always inject with your own 'protected space'—possibly marked out with newspaper—into which no one else is allowed' ('Avoiding viral infections: part II', The Hep C Review Harm Minimisation Poster Series, Hepatitis C Council NSW, 2006).

'If someone else is going to inject you, make sure they ALWAYS wash their hands first' ('Safer Using Tips:

Steroids', Inner South Community Health Service, Safer Using Series, 2000).

Other injecting practices

Some other hepatitis C prevention messages also featured less commonly than those described above. These were usually related to injecting practices and preparation and went into greater detail about specific preventive steps and considerations. For example, people who inject were sometimes implored to prepare in advance, making sure clean equipment was always on hand (e.g. 'Plan ahead: have your own injecting kit so you'll never have to share; get to know locations and opening times of NSP and pharmacies; have a back-up supply; have everything you need before you mix up' ('Safer Using on the Street', Inner South Community Health Centre, Safer Using Series, 2000)). Also to mix up one's own drugs to ensure clean equipment has been used (e.g. '...don't inject hits prepared by other people at some other time' ('Hepatitis C: What you need to know', Hepatitis C Council NSW, 2001)).

Advice or instruction to safely dispose of used injecting equipment infrequently featured in the context of hepatitis C prevention (to prevent chances of reuse). An encouragement to dispose safely was instead sometimes included as a moral obligation to avoid contributing to negative community perceptions of drug users, such as: 'Leaving used equipment around the house or in public can cause needlestick injuries and projects a poor image of drug users' (Safe Disposal, Inner South Community Health Service Safer Using Series, 2001).

The handful of resources which were aimed at women also address injecting in the context of (heterosexual) relationships – where the woman may not have full control over drug purchasing, preparation and consumption - and give advice to 'take control' (e.g. 'Take control of your own drug use - often men initiate women into injecting drug use and control women's drug-use behaviour. This can mean that women often go second when injecting, or are injected by the man. Setting simple rules such as no shared equipment can help. If your partner cares, they will not want to put you at risk' ('Women and hepatitis C: A resource for women with hepatitis C', Australian Hepatitis Council, 2004)).

Environmental/structural/social considerations

Prevention advice was rarely given with consideration of influencing factors exogenous to individuals. Many proximal and distal factors can directly and indirectly impact on an individual's ability to practise the safer injecting advice/instructions presented in the print resources. The legal, policy, economic, social and cultural environment all factor in people who injects' ability to

adopt safer injecting practices and decision-making regarding prioritising hepatitis C prevention.

However, safer injecting advice given in some materials took into account some barriers to accessing equipment/resources and presented an alternative course of action. These considerations reflect the input of drug user organisations in providing insight into the varying conditions under which people may be consuming drugs. Examples of conditions which may prevent safer injecting practices and suggested alternatives is provided in Table 2.

Framing of responsibility for prevention

The responsibility for prevention of hepatitis C transmission was almost always framed as the individual's. This is achieved through the inclusion of directives for individuals to prevent transmission which either directly or indirectly address the intended reader (people who inject, people with hepatitis C). Examples include:

'If you are infected with hepatitis C your blood is infectious. Thus you must be extremely careful not to let other people come into contact with your blood' ('Hepatitis C', Australian Gastroenterology Institute, 1991).

'People with hepatitis C should not... donate blood, share needles/syringes' ('Hepatitis C Factsheet, NSW Health, 1992, original emphasis).

'Any shared equipment could expose you to hepatitis C infection' ('Hepatitis C information: what is hepatitis C?', ACT IV League, 1997).

'How are you going to inject and protect yourself against blood-borne viruses?' ('Safer Using on the Street', Inner South Community Health Service, 2000).

Individual responsibility was sometimes invoked not only to protect oneself from infection (and/or reinfection), but also extended to others. For example:

'To avoid infecting others take steps to reduce opportunities where other people come in contact with your blood, and you should avoid contacting the blood of others' ('Contact: hepatitis C diagnosis booklet', Hepatitis C Council QLD, 1998).

'Learn how to look after your health and that of your mates' ('Staying healthy on the inside', Family Planning QLD, 2003)

One resource asserts that some users who wouldn't use someone else's used equipment themselves may not think twice about allowing someone else to use theirs and discourages this – invoking a moral obligation to protect others from transmission risks:

'Many people who wouldn't risk using someone else's equipment will let other people use their fits, filters etc. Besides giving the impression that you think it is OK to share, this is putting the people who use second

Table 2: Ways of managing conditions prohibitive to safer injecting suggested in hepatitis C educational materials

Issue identified	Alternative	Example
No access to sterile needle/syringes	1. Wait until can get one 2. Use another route of administration 3. Clean your own used fit 4. If there is no other way - clean someone else's used fit	'FROM BEST TO WORST': 1. Use new injecting equipment every time including new fits, sterile water, new swabs, a clean spoon, tourniquet, filter and a clean injecting space and clean hands. If you can't get a new fit.. 2. Choose to wait until you can get a new fit. 3. Try using your drugs another way e.g. smoking, snorting, swallowing or stuffing (up ya bum). 4. Clean a fit that only you have used before. 5. As a last resort...clean a fit that someone else has used' ('When there's no other way... cleaning fits', AIVL, 2003)
Lack of access to tap water & soap to wash hands	Use alcohol swabs to clean hands	'Use another swab to clean your fingers if you haven't been able to wash them' ('Hepatitis C Information Kit', Hepatitis C Council QLD, 2003)
Lack of access to sterile water for drug preparation	Use cooled boiled water	'If no sterile water, use cooled boiled water in a clean glass' ('Safer Injecting', AIVL, 2003)
Lack of access to a clean space to prepare drugs (or soapy water to clean surface)	Lay down a paper bag	'Use soapy water to wipe down the surface, or lay down a paper bag' ('Safer Injecting', AIVL, 2003)

hand equipment at risk' ('Avoiding infecting others', The Hep C Review Harm Minimisation Poster Series, Hepatitis C Council NSW, 2008).

In these examples, individuals are encouraged to consider the welfare of their injecting networks and to assume individual responsibility for (or participation in) the behaviour or practices of others. In a couple of resources responsibility is also placed on the individual to make sure they do not pass on 'bad habits' to new/young injectors and thus protect them from infection risk.

Only a couple of resources framed the responsibility for hepatitis C prevention more broadly – as a community concern. For example in the brochure 'Hepatitis C is everybody's business':

'Around the world, transmission of the hep C virus is prevented by: screening blood donations, providing sterile injecting equipment and education to people who inject drugs (harm reduction)...' (Multicultural HIV/AIDS and Hepatitis Service, 2003).

Assumptions/absences

Materials and prevention messages were reviewed for gaps/absences and assumptions made. In almost all the materials there was the underlying assumption that the target audience has sufficient access to the resources (e.g. sterile needles/syringes, a private space to prepare and inject drugs) required to adopt the safer injecting practices advised. Exceptions include materials specifically targeted at prisoners, where the restricted environment was the prime consideration of advice imparted, and materials which presented a hierarchy of options to consider in the face of limited resources. The latter were commonly developed by (or with acknowledged input from) drug user organisations who have most likely influenced message development to be more practical and realistic in the face of adverse environmental and structural conditions.

A number of materials also instructed the reader to access a needle and syringe program, yet information about where or how was not always included. It is possible that these resources were developed with the intention of being distributed from needle and syringe programs, and therefore assuming people who inject are already aware of how and where to obtain new injecting equipment. Differing local contexts also impact on individuals' ability to undertake safer injecting practices. Most materials appeared to be written with a city-based, resourceful and knowledgeable subject in mind, without regard for the limited access points and range of materials available in regional or rural areas, or influences such as stigma and discrimination in accessing services. Again, however, these materials may have been specifically targeted and distributed at city locations; the intention is unknown.

Aside from the above assumptions surrounding individual agency and resource access, there were also some assumptions around comprehension of jargonistic terms and phrases. Some of these were discussed earlier in the 'key prevention messages' section. In addition, many materials used medical terminology and descriptions when describing hepatitis C, symptoms, transmission and treatment. While it should not be assumed that people who inject all have low levels of literacy, epidemiological research shows that a significant number of street-based people who inject have lower than Year 9 schooling and educational materials should possibly be developed at a 7th grade reading level (Johnson et al., 1997; Grau et al., 2009). This can be achieved without patronising all people who inject by developing all resources at a low literacy level, but by avoiding medical jargon and by explaining key concepts simply and clearly.

Hepatitis C information and prevention messages have changed over time, reflecting the evolving knowledge base since the identification of the virus. Since our sample included materials which were developed in these early days of hepatitis C 'discovery', it is to be expected that some absences in (now current) knowledge would be found in these early materials. For example, messages which explicitly address the potential for hepatitis C reinfection do not appear until 2000. However, even beyond 2000 mention of the possibility for reinfection does not always feature and when it does, only reinfection is dealt with, not 'superinfection', with a couple of exceptions.

Similarly, with regard to testing for infection status, some early materials convey confusing information; presenting antibody tests as conclusive evidence of current infection. In some later materials PCR/RNA (viral) testing is introduced – most commonly featuring in materials which present a comprehensive overview of hepatitis C, from category I described earlier. With the exception of these comprehensive booklets, different testing types and the meaning of results are often not well explained or are completely absent.

Language

The vast majority of materials address the individual directly and use instructive/directive language in relation to hepatitis C prevention tips. They give key instructions to the individual to avoid transmission, for example:

'If you are injecting drugs, do not share any equipment' (emphasis added) ('Tips for living well with hepatitis C in rural South Australia', Hepatitis C Council SA, 2007).

'Don't share your bloody equipment' (emphasis added) ('Hep C: bloody little fact book', Hepatitis C Council QLD, 2007).

'Keep your personal equipment separated from others' (emphasis added) ('Legal and health implications of injecting others', TasCHARD, 2007).

In fewer, but still a considerable number, of materials a group subject is addressed:

'People are advised to make injecting as sterile as possible...' (emphasis added) ('Hepatitis C Factsheet: preventing transmission', Hepatitis C Council NSW, 2000)

'If people are going to inject in prison it is recommended that each time before injecting, equipment is cleaned by...' (emphasis added) ('Hep C and us mob', Aboriginal Health and Medical Research Council of NSW, 2006).

It was common for materials which start by addressing a group subject to switch to addressing an individual subject when imparting safer injecting advice to prevent hepatitis C transmission.

'For *people* who inject drugs... Always wash your hands before and after injecting' (emphasis added) ('Hepatitis C: the facts', Victorian Government Department of Human Services, 2006).

A handful of resources use inclusive language, addressing a hypothetical community (e.g. 'we always use clean needles and never share' (QuIVAA, undated) and 'Just because we can't always choose where we inject, we *can* choose to do it as safely as possible... All we need to do is...' ('Can't choose where, can choose how', AIVL, 2004).

Materials aimed more broadly (general community) as an information resource on hepatitis C, rather than a prevention resource per se, are more likely to be 'informative' in the provision of prevention information. For example: '...common ways people become infected with hepatitis C include: sharing or reusing of injecting equipment...' ('Impact: hepatitis C information', Hepatitis C Council Victoria, 2003) or 'Injecting drug users are at risk of contracting blood borne viruses if they share injecting equipment' ('This is bloody serious', Inner South Community Health Service, 2000).

In early materials the language utilised is more formal but as resources become more targeted over time more slang is used to appeal to the target group. For example, early materials may use the term 'needles/syringes' but later ones aimed at people who inject will use the term 'fits'. Other changes in language include using the term 'mixing up' for drug preparation, 'hit' or 'shot' for injection of a drug. Similarly, materials aimed at other specific target groups, including ATSI, prisoners use slang commonly used in these communities.

Despite this, many materials retain the use of technical language in describing the hepatitis C virus, symptoms and treatments, while switching to simple and straightforward language in prevention advice sections. In materials with comprehensive information, a glossary is often included.

Design/images

While standard A4 size fold-out pamphlets and A5 booklets were the most common format in this sample, materials produced in later years became considerably more creative, utilising different formats (e.g. wallet fold-out cards, postcards, bookmarks, comics, posters), sizes, and a variety of fonts and striking colours, making them more eye-catching and unique (and probably reflecting improved technology and access to desktop publishing by community organisations). This was particularly the case for materials which was aimed at young people but also generally for people who inject. This can be seen as fitting into the tenets of a social marketing approach to health communication (Andreasen, 1994).

While colourful design and innovative presentation became common, the use of imagery to represent injecting drug use did not. Where images were included, they were often utilised to illustrate a point, or advice being given – such as steps to safer injecting and items which may have got blood on them. In these cases, close-up 'clipart' type images featuring only body parts were often used to demonstrate each step being described, or warned against. For example, an arm with a tourniquet around it, a vein with a needle/syringe hovered above. This most likely reflects the limitations generated by needing to conform to a degree of social acceptability in the production of resources.

Currency of information

Some of the materials in this sample included information that was out of date and therefore inaccurate. This most commonly related to the treatments available for hepatitis C, and requirements to receive treatment. This is an area that has changed rapidly in recent years so it is to be expected that the earlier materials were not up to date. However it is of concern that out of date materials were still in circulation.

Some organisations regularly included a date on which the resource had been most recently reviewed, allowing the reader to make an assessment on the currency of the information. For example, 'Last reviewed April 2006' (Hepatitis C Factsheet, Hepatitis C Council NSW, 2006). However this was not the norm. A number of materials included a disclaimer about the information included and encouraged readers to seek further advice. For example: 'This booklet was first published in 1996.

Some information contained in it may soon be obsolete as knowledge about hepatitis C is evolving rapidly. Readers are encouraged to contact the Hepatitis C Council of NSW to check that information in this edition of the booklet is still current.' (Hepatitis C: what you need to know, Hepatitis C Council NSW, 1996). Sometimes disclaimers (or caveats) featured as part of the provision of information (rather than a side note on the inside cover), such as: 'Hepatitis C is a relatively new virus and there exist many unanswered questions.' ('A B C Positive??? Viral hepatitis information', Hepatitis C Council SA, 2000), or 'Based on the analysis of the current literature on the progression of hepatitis C, it appears that 65-85% of people with Hep C infection will progress to chronic or

long term infection.' ('Hepatitis C!!!', Hepatitis C Council SA, undated). One pamphlet acknowledges that the field is still learning about Hep C (in 1995) and consequently the messages are not expressed in absolute terms, e.g. 'hepatitis C appears to cause a milder initial infection [than hepatitis B]...' ('The ABC of hepatitis'. Victorian Government Department of Human Services, 1995).

The other area in which information was frequently out of date was the provision of contact details for services and further information. While in the internet age it is considerably easier for people to access contact details for organisations independently, the provision of incorrect contact details presents yet another hurdle for people who inject to access further information and care.

Recommendations

Based on the research findings, the following recommendations are made for the design and distribution of hepatitis C educational materials aimed at people who inject drugs. These relate to all aspects of the conceptualisation, development, design, dissemination and evaluation of hepatitis C prevention resources. They also include the ways in which the target audience is involved in aspects of this process.

Note: The review was designed to be a critical analysis of the existing range of HCV prevention resources aimed at people who inject. The criticisms raised in this review are intended to be constructive, and thus contribute to a common aim to improve the overall quality and relevance of health promotion messages. However, this is not to disregard the social and structural constraints on the production and packaging of HCV prevention messages. Also, this review was unable to identify the local context of individual resource production, the rationale for inclusion or exclusion of certain information, or other decisions. Overall, the catalogue of resources reviewed in this sample was of a good quality, reflecting the professionalism, commitment and conscientiousness of the sector.

Responsibilities, limitations and access

1. Acknowledge that responsibility for prevention is shared

Hepatitis C prevention messages should seek to avoid blame, which can reinscribe stereotypes and stigma. Consideration should be given to balancing individual responsibility and shared responsibility for prevention. Individual responsibility for hepatitis C prevention needs to be contextualised against the wider responsibilities of organisations, governments and society. This can be done, for example, by outlining the measures governments are taking to address hepatitis C prevention, and by framing people who inject as partners in the wider response.

2. Consider the restrictions of the local environment (including injecting environment and supply of equipment)

Prevention advice should be realistically achievable by the target group. For example, local factors, such as the availability of needles/syringes or sterile water, influence individual ability to undertake the safer injecting practices promoted. Incorporating suggestions for practice which are unachievable because of local context issues can reduce the credibility and usefulness of the health promotion resource or activity.

Message targeting

3. Repackage for specific target groups

Messages should be tailored with consideration of the diversity of people who inject, taking into account that many may not identify as part of a community of injectors or drug takers. This may mean regularly repackaging information based on the interests of the specific target group. Tailoring messages based on epidemiological risk categories (for example, people who inject in public, people with unstable housing) can be problematic as these categories are not easily identifiable in reality and can include diverse and overlapping populations. Careful planning is needed in the development phase to ensure that messages are appropriately packaged and targeted to avoid alienating or stigmatising groups or practices.

4. Contextualise hepatitis C prevention within the diversity of injectors' experiences

Didactic messages can be perceived as patronising, and traditional prevention advice and methods may be seen as irrelevant by target groups. If packaged with new useful information and other resources, prevention advice can have fresh impact. The principle is to avoid foregrounding potentially bland or unappealing messages by contextualising hepatitis C prevention

within people's lives more generally. Going beyond traditional print-only educational resources and campaigning to create innovative ways of distributing information could aid in attracting renewed interest from the target group. The relevance of standard prevention messages can be increased by including other useful materials or messages. For example, one resource (not included in this review of print materials) consisted of a toiletries bag and toiletries, which also included hepatitis C prevention information. This may also be a way to interest new injectors who may not relate to traditional methods of education. Other messages shown in the social research literature to be supportive of safer injecting practices include those relating to health and social issues beyond hepatitis C itself. For instance, it is important to recognise that some people who inject drugs consider track marks, their visibility, and the stigma they can attract, a more significant issue than hepatitis C. Likewise, some readers may be more concerned about building and maintaining healthy and workable social relationships whilst managing drug use, or managing the financial aspects of drug use to avoid withdrawal symptoms. Others again may be most interested in promoting hygienic practice in injecting (to prevent 'dirty hits' and to maintain hygienic practice and general health).

Digital communication mechanisms may also offer novel ways of accessing new and young injectors and provide new possibilities for the tailoring, packaging and delivering of information.

5. Address injecting in groups

Further attention could be paid to group injecting situations; social conventions related to injecting can impact on individual ability to enact safer injecting practices. Within groups, individuals may have specific roles as determined by their relationships with others present, especially as this relates to gender and intimate relationships. Also, the injecting setting may influence who has the ability to shape practice (e.g., when injecting occurs at an individual's home).

6. Ensure input from a number of sources, particularly the target group, in resource development

Peer involvement is essential at every stage of message development. All messages developed should have input from a number of sources balancing best available information and insights from the target group with knowledge drawn from social research in hepatitis C prevention and the broader health communication literature. This balance will limit the risk of reproducing stereotypes about people who inject drugs and their practices.

Approach

7. Policy support for future resource development

Policy should support conditions that not only facilitate the timely and accurate design and delivery of messages, but also 'safer injecting environments' themselves. For example, policy should not hinder a community response to emerging health issues by censoring messages considered politically unpalatable. Further, there is a need for NSW Health to undertake a program of communication about policy and processes concerning resource development, distribution and approval. This will enhance stakeholder understanding of what is involved in the approval process, and minimise the potential for misconceptions about constraints that may lead to diminished breadth or innovativeness in resources.

8. Currency and timeliness of information

Materials in distribution should always be up to date. Knowledge about hepatitis C and treatment changes rapidly. All resources should therefore include a date of publication and a recommendation to review by a set future date. A supporting strategy involving the recall of out-of-date materials should also be built into resource design and funding, to minimise the continued circulation of materials that are no longer accurate. These publication and review dates should be clearly written on the resource, so they are visible to readers. Further 'caveats' could also be embedded in the text, making clear that the information is subject to change and update, for example, expressions such as 'based on what we currently know...' could be used.

9. Use of plain language and avoiding jargon

Prevention messages and transmission descriptions should not presume that readers understand jargonistic terms and phrases (e.g. 'blood-to-blood contact', 'acute'/chronic' hepatitis C infection). They may be a source of confusion as they do not provide adequate descriptions. Simple, non-technical language can help to carry a message clearly and without confusion.

10. Use of conditional rather than absolute language to promote mindful practice

Absolute language limits alternative ways of interpreting and applying the information being presented. Resources should aim to make greater use of conditional language; this means changing directives such as 'never' and 'always' to words such as 'perhaps', 'possibly', 'typically' and 'one way of...'. For example, the following sentence promotes

thoughtful engagement: ‘it is important to consider whether any pieces of equipment might have been used by anyone else. Could the water you have been using for mixing up have been used by anyone else? If you are unsure, and there is more water available, it is better to get water that you know is clean and hasn’t been used by anyone else’.

11. Ensure an evaluation strategy is in place

Evaluation of resources should be built in from the outset of resource design. The development of strategies to assess the distribution and uptake of the materials, as well as structured feedback on their perceived value and their use, should be part of the development process.

12. Resources should be focus tested with members of the target audience

In that health promotion messages can themselves reproduce stereotypes and stigma, it is important to recognise that they can do worse than be ineffective. Where it involves members of the target audience as key collaborators, focus testing of resources helps to identify ways in which targeted readers interpret messages. Ideally, focus-testing is best facilitated by an appropriately trained member of the target group.

While focus testing is essential, it does not insure against ineffectiveness or introduction of damaging stereotypes. As with all publicly funded publications, hepatitis C health promotion literature has a responsibility to avoid sexist, racist and other derogatory representations, even where those representations circulate within the target readers.

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Appendix 1

Framework of analysis

General information

Who is the document produced by?

- author?
- single or multiple contributors?
- how was it funded? (if available)
- why was it produced (in response to a particular issue/behaviour/to meet funding requirements of a project etc)

What was the date of production?

Any indication of edition or revision number, or use-by date

What logos / badging does it carry? (eg indication of Health Dept endorsement)

Design/Presentation

What form does the document take? (e.g brochure, card etc)

Are there images included, and if so...

- what is depicted?
- if people are depicted, how are they presented and what do they convey? what is their environment?
- what objects are depicted and what do they convey?
- use of photographs / line art / cartoon art to portray people, gear etc

How are text/images used together/separately? effect of this?

What and how are font/s, colours used?

- use of bold, capitals, underlining, italics? intention and effect of this?
- amount or density of text — eg narratives / expositions vs bullet point lists / catch phrases, slogans etc

Content

Is the document focussed only on hepatitis C (or also hepatitis B, HIV)?

- are the viruses dealt with separately or together?

What are the key messages?

- what advice/directives are given around injecting and hepatitis C prevention?
 - is there uncertainty? how is it handled?
 - what is emphasised and how?
- do the messages assume individual agency?
- what other messages are conveyed and how?
- which non-injecting 'risk behaviours' are addressed?
- is the message clear?

Do the messages align with or reflect current knowledge surrounding hepatitis C?

How is the injecting environment dealt with (if at all)? Are other structural and social constraints addressed?

What language is used?

- how does the language used shape the messages?
 - tone?
 - use of street language / slang
 - use of technical/medical terminology
 - is terminology explained (use of glossary, footnotes, side bars, boxes, etc)
- how is language utilised to target specific groups and how does it gain attention?
- does the resource effectively match with the anticipated learning styles and capabilities of the target group?
- does the document address individuals/groups/couples?
- use of author voice (e.g. us/you/me)
- is the language instructive/directive, inclusive, suggestive/advisory?
- is the document appropriate for people with low literacy? (why/why not)

How is responsibility for prevention framed? how?

- individual? shared? organisational?
- accountability?
- division between 'at risk' groups and general community?

What changes are advocated?

Are harms other than hepatitis C or B and HIV addressed? (including injecting-related injury and diseases, social harms) How are they dealt with?

What referral information is included in the resource... organisations and services contact info; other references or resources, websites, etc

Target group/s

Who, or what group, is being spoken to?

- how is this achieved?
- are certain groups included/excluded and how?
- is the source credible to the target group?

How is the target group constructed/characterised?

Are stereotypes reinforced or challenged? how?

Other

What is absent/unsaid?

What assumptions are made?

How are injectors situated? Does the user's voice feature? (does this lend or detract credibility?)

What is assumed about the position of the reader and their reception of information?

What referral information is included?

Appendix 2

Summary of resources evaluations

Main questions of evaluation

- Questions around tone, imagery, readability and layout used – did this connect & engage target audience?
- Questions around appeal, approval, culturally appropriate, accessibility, acceptability, realism, relevance, resonance to the target audience
- Target audience recall of information contained – influence behaviour change?
- Measuring of hepatitis C transmission knowledge, awareness, comprehension & understanding – can this learning be linked to the resource?
- Could target audience understand the resource? Appropriate literacy level?
- Was the chosen ‘medium’ appropriate and acceptable for the target audience?
- Distribution of resource within peer network? Use as a ‘peer education tool’?
- Measure changes in injecting practice & risk related behaviours as a result of exposure to the resource
- Questions around the distribution of the resource - scope, type of agencies distributing, quantity distributed, uptake by target audience
- What was the ‘take home’ message received by the target audience? Was this ‘take home’ message the same as the ‘key message’ developed by the resource producer? Did the resource successfully meet target audiences learning needs?
- Usefulness and how the resource was used as an engagement tool by health professionals
- Evaluation should clearly identify why the resource was produced and assess as to whether the resources objectives were clearly delivered

Focus of evaluation

Impact & Outcome

- Reach of resource – had resource been distributed to the appropriate agencies & viewed by target audience?
- Usage patterns by target audience & health care workers
- Measurement of resource/messages passed on to peers or others within network?
- Were there any notable and/or significant; increases in knowledge around hepatitis C transmission & risk factors, decrease in ‘risk’ behaviours associated with hepatitis C transmission, improvements in injecting practice. Were these changes directly or in part attributable to the resource?
- Measurement of increases in needle and syringe program distribution levels

- Identified limitations and challenges of measuring and attributing changes in injecting practice and overall reduction of hepatitis C infections to a specific hepatitis C prevention resource

Process – would be conducted with a quality improvement perspective

- How were the resource’s project development group members recruited & established? How were stakeholders engaged through the resource development process? Quality of stakeholder consultation?
- Were the appropriate stakeholders consulted (e.g. experts, researchers, target population)
- Was the resource rigorously/appropriately focus-tested with the target audience throughout the development process?
- Examination of issues that arose through the resource development process
- Evaluation of partnerships
- Have original aims of the message been retained throughout the resource development process?
- Effectiveness of resource distribution & support strategies
- Evaluation focus upon development, improvement & strengthening future productions

Use of evaluation findings

- As advocacy tools to attract future funding & initiate future resources/projects
- Identify new or develop existing areas of work – identify gaps in client/worker knowledge and hepatitis C transmission risk behaviours
- Direct current service delivery
- Develop & direct future health promotion resources – what works? Is there a medium which the target audience identify as appealing, attractive or acceptable
- Inform & influence local AHS and state-wide policy
- Enhance knowledge and professional development of the hepatitis C/blood-borne virus prevention sector – share what has been learnt with other health workers undertaking resource development
- To argue for the commissioning of new services, expansion of existing services
- To inform distribution and targeting of future messages & resources

Ways in which messages for resources are currently developed

- Informed by research (social, epidemiological, clinical trials) & reviewing literature for evidence to support

message - information gathered from National Needle and Syringe Program Survey, periodic reports by NSW Health, ANEX Needle and Syringe Program forum

- Messages developed and directed by Dept of Health resource approval guidelines
 - Consultative method development process with stakeholders, incl.; people who inject drugs, peer organisations, key bodies, specialists, project 'reference' groups, other health professionals, researchers
 - Messages developed through the identification and understanding of the target audiences learning needs
 - in response to and to correct misconceptions about hepatitis C transmission
 - Hepatitis C prevention messages developed through emerging need and by services response e.g. changes drug use patterns, client injecting practice, behaviours associated with injecting, newly identified 'at risk' population groups, worker & service observations, clinical presentations
- Use hepatitis C prevention messages produced by national & state-wide organisations and then packaged by smaller services meet local need
 - Identifying injecting related research, key findings, recommendations and how they can be translated into messages for clients
 - Sourced from workforce development events
 - Look toward relevant theme based health campaigns - Hepatitis Awareness Week
 - Formal and informal 'focus testing' & 'canvassing' of clients through opportunistic conversations between worker and client
 - Workers have individual approaches to develop messages e.g. some workers are influenced by evidence/research. Other workers approach focuses more upon how messages can be made interesting and their capacity to engage
 - Messages developed from worker/service expertise and interest