

# Lives of Substance: A mixed-method evaluation of a public information website on addiction experiences

Carla Treloar\*, Centre for Social Research in Health, UNSW, Sydney, Australia

Kiran Pienaar, Social Studies of Addiction Concepts, National Drug Research Institute, Curtin University, Melbourne, Australia; School of Social Sciences, Monash University, Melbourne, Australia

Ella Dilkes-Frayne, School of Psychological Sciences, Monash University, Melbourne, Australia

Suzanne Fraser, Social Studies of Addiction Concepts, National Drug Research Institute, Curtin University, Melbourne, Australia

\* **Corresponding author contact details:** c.treloar@unsw.edu.au

**Please cite as follows:** Treloar, C., Pienaar, K., Dilkes-Frayne, E. & Fraser, S. (2017). Lives of Substance: a mixed-method evaluation of a public information website on addiction experiences. *Drugs: Education, Prevention and Policy*, 1-8. doi: 10.1080/09687637.2017.1397602

**Note:** This article may not exactly replicate the final version published in the journal. It is not the copy of record. The final published version can be found here: <http://www.tandfonline.com/doi/full/10.1080/09687637.2017.1397602>

## Abstract

### Aims

The Lives of Substance (LoS) website presents personal experiences of drug use and ‘addiction’ in people’s own words as part of a larger project of complicating public discourses of addiction, countering stigmatising misconceptions and acting as an intervention in the social production of addiction. This article presents the findings of a mixed-method

evaluation of the website, and comments on some of the methodological and practical challenges of evaluating health-related online information resources.

## **Method**

Three data sources were used to examine: the reach of the website (website analytics); experiences of the website audience (responses to an evaluation survey on the website); and, other indicators of use and impact (including social media referrals and organisational links).

## **Results**

In the 10 week evaluation period, 3970 unique users visited the website. Comments provided via the online survey endorsed the website as a means of challenging stereotypes and as presenting drug use as only a 'part of a person's whole life'. Twenty-four organisations had linked to the website and 987 social media referrals were recorded.

## **Conclusion**

These data indicate that the LoS website is having some success as a resource for countering addiction-related stigma and offering more holistic and inclusive social understandings of addiction.

**Keywords:** Addiction; evaluation; website; personal experience

# Lives of Substance: A mixed-method evaluation of a public information website on addiction experiences

## Introduction

This paper describes the development and evaluation of an innovative new website featuring personal accounts of alcohol and other drug addiction, presented in people's own words. The website, [livesofsubstance.org](http://livesofsubstance.org), was developed by the authors as one outcome of a research project funded by the Australian Research Council. The site was designed as a means of presenting the findings for workforce and public audiences. Drawing on qualitative interviews, [livesofsubstance.org](http://livesofsubstance.org) offers a range of personal stories drawn from 60 adults living in Australia who describe themselves as having an alcohol or other drug addiction, dependence or habit. The personal stories are presented in the form of de-identified participant biographies, carefully reconstructed from the in-depth interview material. Also presented are key themes found in the interviews, including everyday life with an addiction, dependence or a drug habit, managing regular drug use, coping with stigma and discrimination, and seeking help or initiating change. Using original audio recordings, video re-enactments and text extracts from the interviews, the website presents these experiences accessibly and vividly, showing participants as whole people with complex rich lives. Further details of the theoretical and methodological underpinnings of the website have been elaborated in previous articles (see Pienaar et al., 2015, which describes the website as an intervention in the social production of addiction; and Pienaar & Dilkes-Frayne, 2017, which discusses the methodological decisions guiding the composition of the website biographies).

Before describing the website evaluation findings, it is necessary to provide some background to the development of the website and its evaluation by situating it within the

social science literature on addiction. Concepts of addiction vary across time and place and the term ‘addiction’ itself is heavily contested, its meaning subject to continual revision (Keane, 2002; Room, Hellman, & Stenius, 2015). How addiction is understood in the medical domain is in flux, with changes occurring in diagnostic criteria in recent times (Dwyer & Fraser, 2016b; Fraser, Moore, & Keane, 2014; Room, 2011) and as neurobiological disease models gain prominence (Vrecko, 2010). Researchers find defining addiction as a stable condition or disease difficult, and many resort to broad multifactorial models as a means of preserving the category (Griffiths, 2008, 2009; Halkitis, 2009; Martin, Weinberg, Bealer, & Martin, 2007). Many criticise neurobiological accounts, drawing attention to the limits and potentially deleterious effects of treating addiction as a brain disease (Carter & Hall, 2012; Dingel, Karkazis, & Koenig, 2011; Kalant, 2009; Morphet, Carter, Hall, & Gartner, 2017; Vrecko, 2010). There is also a body of transdisciplinary research that seeks to bridge biomedical and social scientific conceptions of addiction, highlighting the complexity of ‘addiction issues’ and the value of bringing different disciplinary insights to bear on efforts to understand and address these issues (Greaves, Poole, & Boyle, 2015; Kaye, 2012; Kushner, 2010).

Outside the academic domain, popular accounts of addiction circulate constantly in the media, including depictions of high profile individuals, or celebrities presented as affected by addiction (Seear & Fraser, 2010; Tiger, 2015). With the advent of social media and online sources, lay experiences of addiction are also being increasingly widely promulgated (Dwyer & Fraser, 2016a; Pienaar et al., 2015). What is common across these different portrayals is the reliance on stigmatising and stereotypical narratives of trauma, collapse and redemption that characterise addiction as a uniformly pathological trajectory (Ahern, Stuber, & Galea,

2007; Brener, von Hippel, von Hippel, Resnick, & Treloar, 2010; Fraser & valentine, 2008; Radcliffe & Stevens, 2008; Room, 2005; Treloar & Holt, 2006). By extension, as critical social research has shown, those seen as affected by addiction are stereotyped in these accounts as chaotic, disordered and incapable of exercising agency (Fraser & Moore, 2008; Seddon, 2007). Baseless public fears and negative reactions to drug use have a profound impact on people who use drugs and can act as a barrier to seeking help where it is desired and contribute to ongoing health inequalities (Hatzenbuehler, Phelan, & Link, 2013; Lloyd, 2013; van Boekel, Brouwers, van Weeghel, & Garretsen, 2013). Critical scholarship on drug use and addiction challenges these stereotypes by demonstrating that simplistic equations of addiction with compulsion and loss of control are socially and culturally constituted, rather than natural or inevitable (Berridge, 2013; Room, 2003; Weinberg, 2002). Destigmatisation efforts have been called for in the public, media, police and treatment spheres to challenge stereotypes and negative language, encourage people to speak out about their personal experiences, and address the negative effects of marginalisation (Livingston, Milne, Fang, & Amari, 2012; Lloyd, 2013; Tindal, Cook, & Foster, 2010).

Building on this socio-cultural research, other scholars have tracked how addiction functions as a powerful mechanism of social control to classify and discipline subjects (Fraser, 2006; Fraser & valentine, 2008; Netherland, 2011; Smith, 2010). This body of literature offers valuable insights into the social production of addiction but it leaves open the question of how addiction takes shape through personal experiences of regular drug use and the meanings people attach to these. Moreover, what has largely been missing, until recently, is a scholarly and critical social science of drug use and addiction that allows for a greater range and diversity of experience and outcome (Weinberg, 2011). Addressing this issue, Fraser *et al.*

(2014) challenge conventional understandings of addiction, which treat it as an established medical fact or pre-existing problem with predictable, measurable individual and societal costs. Instead they theorise addiction as an unstable phenomenon made in practice, including through our efforts to understand it and, importantly for our purposes, through individual but socially shaped experiences of drug use (Fraser et al., 2014).

Aiming to address gaps in public understandings and contribute to the growing body of critical scholarship on addiction, the project on which [livesofsubstance.org](http://livesofsubstance.org) was based began in 2014. Funded by the Australian Research Council and drawing on the expertise of a large national advisory panel, the project collected the personal accounts of people who describe themselves as having an alcohol or other drug addiction, dependence or habit. A collaboration with Healthtalk Australia, an Australian research consortium that conducts qualitative research into personal experiences of health and illness, the project used a research methodology developed by Oxford University's Health Experiences Research Group (Health Experiences Research Group (HERG), 2010). Following this methodology, purposive data collection and in-depth qualitative interviewing were used to collect personal accounts from 60 people who responded to a recruitment flyer that opened with the question: 'Do you consider yourself to have a drug habit, dependence or addiction?' Those who responded were screened to ensure they reported a pattern of alcohol or other drug consumption that would qualify them for a diagnosis of 'substance use disorder' or 'dependence syndrome', the terms for 'addiction' in two influential diagnostic instruments, namely the Diagnostic and Statistical Manual (*DSM-5*) (American Psychiatric Association, 2013) and the International Classification of Diseases (ICD-10) (World Health Organization, 1992). They were also screened to ensure variation in gender, age, drug type(s) consumed, and treatment

experiences. The study was approved by [omitted] Human Research Ethics Committee (HR 55/2014). All participants provided informed written consent.

Following an open-ended invitation to ‘tell us their story’, they were asked about their experiences of living with an alcohol or other drug habit, dependence or addiction, including the terms they use for their own experiences, how consumption fits into daily life, managing health and well-being and future plans. Interviews were audio-recorded and transcribed verbatim. To protect participant identities, each was given a pseudonym and all identifying details were removed from the transcripts.

The interview data were then carefully analysed to create a rigorously produced dataset for a new online resource, [livesofsubstance.org](http://livesofsubstance.org). The aim was to 1) present a more nuanced and sophisticated public discussion of addiction; and 2) make an original contribution to the social and cultural production of addiction concepts (Pienaar et al., 2015). In doing so, the project theorised addiction as a socially and historically contingent phenomenon, one that emerges through, rather than precedes, particular social norms and practices, such as public debate (Fraser et al., 2014). The website was designed to engage diverse audiences including people with experience of drug use, family members, health workers and policymakers.

In developing the website content, participant biographies (or ‘Personal stories’) were reconstructed from the interview material, and care was taken to exclude identifying or sensitive details. Importantly, all participants were given the opportunity to check and approve the biographies produced from their interviews. Designed to present a variety of

experiences, the biographies avoid typical ‘rock bottom to redemption’ narratives and include participants’ accounts of the pleasurable and beneficial aspects of drug use as well as its difficulties and challenges (Pienaar et al., 2015). On the website, each participant biography is accompanied by several video re-enactments, original audio clips or text extracts from the interview. Also presented are summaries of key topics (e.g., ‘What is addiction or dependence?’, ‘Dealing with stigma and discrimination’, ‘Everyday life with an addiction, dependence or drug habit’, ‘Looking after health and well-being’, ‘Treatment, self-help and other responses’) with clips to illustrate main points. The project was conducted within a framework of engagement – key stakeholders, including representatives from drug user organisations, service providers and policymakers were convened to form an advisory panel that met twice a year. They provided important input into participant recruitment, data collection and analysis, and dissemination of findings. They also provided quality assurance of the material presented on the website, including reviewing selected biographies and summaries of key topics.

In this paper we present an evaluation of [livesofsubstance.org](http://livesofsubstance.org) to examine its progress towards the overall aims of the project, that is, to enhance public discussions of addiction, counter stigmatising misconceptions and promote understanding of the diverse experiences of those who see themselves as affected by it. In presenting a wide range of experiences, our aim was not to dismiss or minimize individual suffering and struggles. Rather, in articulating these experiences, we sought to present them in the context of people’s whole lives. Doing so draws attention to the ways in which addiction experiences and their effects are bound up with other social and political issues, such as marginalisation, poverty, violence, isolation, stigma and institutional neglect. The evaluation’s mixed method approach drew on the following components: (1) website analytics to identify the number of website users, page



views, sessions and proportion of new sessions; (2) responses to the embedded survey; (3) other indicators of reach and impact such as links to the website from other sites, social media mentions and inclusion in professional sector newsletters.

## **Method**

The evaluation of a public facing resource such as [livesofsubstance.org](http://livesofsubstance.org) presents many challenges. Most obviously, evaluation processes can interfere with low threshold access to the site. Comprehensive evaluation of a 'live' site via sign-up or lengthy compulsory questionnaires can deter visitors and engagement. Rather than seeking to elicit responses from specific groups or create samples from clinic populations –the approach taken in previous evaluations of HealthtalkOnline projects (Newman, Ziebland, & Barker, 2009; Rozmovits & Ziebland, 2004; Sillence, Briggs, & Herxheimer, 2003) – this evaluation proceeded 'naturalistically', discreetly inviting those who found their own way to the website to take part in a short survey. In addition to the survey the evaluation drew on a range of methods to examine the reach of the website, experiences of the website audience, and other indicators of use and impact (from social media, organisational referrals etc.). In these respects the evaluation sought to reflect 'real life' use.

[Livesofsubstance.org](http://Livesofsubstance.org) was launched at a public event on 7 October 2016, augmented by a promotional campaign involving distribution of hard and soft copy notices via professional network newsletters; satchel inserts at a national alcohol and other drug conference; social media posts; and a direct mailout of posters and postcards to local health services, community-based organisations, alcohol and other drug treatment services, drug user groups and harm reduction and advocacy organisations. Media appearances were made by team members describing the website and the launch events. Members of the project advisory

panel and team also circulated the promotional materials to their networks. In line with the engagement principles and activities of this project, the launch of the website featured reflections from two people with personal experience of drug use, namely Jenny Kelsall, Chief Executive Officer of Victoria's drug user peer advocacy organisation Harm Reduction Victoria and Kate Holden, the author of a well-known Australian memoir on her own drug use (Holden, 2005). The involvement of these people also provided a means to promote the website to different audiences.

*Website analytics:* Before going live, the website was registered with Google webmaster's online 'Search console' tool to allow tracking of links to it from other sites and monitor its performance. A sitemap was submitted via the online search console to aid indexing the site and to optimise its searchability. A Google Analytics tracking code was embedded in the site and an analytics account created to track and report website traffic.

*Evaluation survey:* The website's home page included an invitation to provide comment on the survey via a short online survey. The survey was promoted on social media for one month following the launch of the site. To preserve low threshold access to the website and address concerns about participant burden, the survey was brief and anonymous. Survey participants were asked to indicate why they were interested in the site, which parts were most helpful or informative, the assistance provided by the site, whether they would recommend it to others, what could be improved and any other comment they wished to make. Age and gender were also recorded. The resulting data were examined using basic statistics (frequencies). The additional qualitative comments made by survey participants were analysed thematically according to the aims of the website. Close attention was paid to comments that touched on

discourses of addiction and challenges to these. Comments relating to functionality of the website were useful for guiding updates and design improvements to the site, but are not within scope of this paper. Given the authors' role in developing the website, particular attention was paid to examining comments that presented negative, critical or dissenting views.

*Other measures of reach and impact:* As this project was conducted within an engagement framework, the uptake of the website is a significant factor to explore in evaluation. Regular monitoring of the website's performance was managed using Google webmaster tools, which provides an online portal showing the top domains linking to a website, and Google Analytics, which tracks and reports website traffic. Social media referrals were also tracked using Google Analytics. Links were collated by relevant organisation (research, service provider and community-based), social media referrals (e.g. Twitter and Facebook), mentions in newsletters of professional networks and other indicators of use (such as in teaching tertiary-level courses).

## **Results**

*Site analytics:* Visits to livesofsubstance.org were recorded for approximately 10 weeks from one week prior to launch. In that time, 3970 unique users were recorded. They viewed 15,803 pages in 5681 sessions. Approximately 60% of these were new sessions. Visitors viewed an average of 2.77 pages per session and the most popular pages were the Personal Stories and Resources and Information pages with most visitors navigating from the homepage to these pages. The average session duration was 3.45 minutes.

*Evaluation survey:* The passive recruitment strategy and short recruitment period of one month produced 60 survey responses. Equal proportions identified as male and female (47%) and 7% indicated ‘other’. Most participants (93%) were aged more than 30 years. Almost all (93%) indicated they would recommend this site to others. Interest in the website was related to professional role, with 33% indicating that they were interested because they worked in the alcohol and other drugs sector and 20% indicating that they were a student or researcher (multiple responses allowed). Fewer people indicated that their interest in the site was related to their own (13%) or others’ drug use (13%). This indicates the early promotional reach mainly to professional audiences. When indicating which parts of the website were most useful or informative, the most frequent response was the personal stories (75%) – a finding that corroborates Google Analytics statistics showing that the Personal Stories pages are the most popular among site visitors. Participants were asked to indicate how the website had helped them understand or respond to addiction. The most commonly endorsed response was ‘Learning about people’s experiences of self-help, treatment or changing consumption practices’ (58%) (Table 1).

In the comments provided by survey participants three main themes arose: challenging stereotypes; authentic representation; and personal impact and use of the website. The website’s aim was to go beyond ‘narrow formulations that offer only shame and renunciation’ (Pienaar et al., 2015) (p 8). Many survey participants praised the website for challenging stereotypes by expanding narrow portrayals of drug use and presenting drug use within the context of whole lives and personal aspirations. These comments reflect an

awareness of the pernicious stigma associated with drug use and point to the value of resources that assert the equal worth of the lives of people who use drugs.

I like the way that drug use is not positioned as the central defining feature of the people on the site. It's good to highlight how drug use is part of a person's whole life which is a complex and worthwhile as the lives of those who do not use drugs.

(participant #25)

This site is extremely valuable as it shows the diversity of experiences of addiction. It challenges stereotypes by presenting individuals who regularly consume substances as whole persons with rich and complex lives. (participant #28)

I liked that the stories I read did not all end with '...and then I stopped using and my life got better.' I believe that the more society acknowledges that positive change can occur regardless of use, the more people will feel prepared to enact some of those changes in their lives. (participant #59)

However, one or two participants were less sure of the website's ability to destigmatise. Because addiction is stigmatised in Australia, and people associated with it face discrimination, the website's interview material was altered to protect the identities of participants. Notably the video clips presented on the website were produced using professional actors who re-enacted the original interview material. The actors were drawn from a diverse range of ethnicities, ages and other backgrounds (to closely reflect the range of study participants), and attention was paid to avoiding stereotypical depictions of people who

use drugs as poor, unwell or uneducated. Still, some survey participants suggested that the use of actors tended to homogenise the presentation of stories.

Because actors are used, I'm not sure whether people from a range of backgrounds would necessarily identify with what the characters say – the few actors I viewed sounded too educated, white, well-turned out. This is positive as it debunks addicts being down-and-out, but it has drawbacks. (participant #46)

One other survey participant expressed concern that the website might reinforce the stigma associated with drug use in assuming the need for anonymity.

if its about decreasing stigma, how about doing it so we (as users) don't have to hide e.g. behind actors. (participant #44)

The potential applications and impact of the website was the third major theme in the comments of survey participants. Two main sub-themes were apparent in these responses: the impact on people who use drugs or those close to them and the usefulness of the website for people working in the field. Two survey participants indicated that that they had also taken part in the Lives of Substance project itself (and their stories were thus on the website). Both were supportive of the project and its aims. Participant #40 acknowledged that she was 'not quite ready to share' her experiences of drug use with friends, but taking part in the study had been a significant 'milestone' for her. Others reported that the website reduced their sense of social isolation by presenting stories from people with similar experiences.

I was a participant in this project and am excited and relieved to be part of something that gives voice to the lived experience of substance users in all its myriad complexity. (participant #21)

[I] don't feel alone knowing that others have experienced what im [sic] dealing with. (participant #35)

According to the survey results, the website had been shared and used by participants in a range of ways relevant to their circumstances. Many comments were made about the usefulness of the website, and its value as a tool for combating addiction-related stigma. One participant reported sharing the site with peers in addiction self-help groups, specifically noting the importance of its role in tackling stigma.

I have shared this site with my contacts within AA and NA, and really feel that this research will start to unlock the stigma and discrimination towards drugs and addiction. (participant #18)

Also reflecting on her own practices and judgements of those who use drugs, participant #50 noted that the 'balanced view' of LoS helped to challenge her 'stereotypical' responses to people who use drugs. Finally, the usefulness of the website as a teaching aid was also noted.

People with substance dependency have featured in my life and response has been the stereotypical one. I have been harshly judgmental and have condemned the user. This

website presents a really balanced view people who describe themselves as addicted or dependent on substances. (participant #11)

I'm an academic who teaches teachers and drug abuse is a problem at many schools, so I hoped the website would give me fresh ideas about tackling this issue.

(participant #46)

This is a brilliant resource – thanks. I provide AOD-related training in a workforce development capacity and the audio and video clips will be a wonderful way to illustrate information/concepts in presentations (participant #4)

*Other indicators of reach and impact:* At the time of writing, 24 organisations had linked to livesofsubstance.org from their own website. These comprised four harm reduction organisations (two international and two Australian), two national alcohol and other drug policy and advocacy organisations, five alcohol and other drug services (one international and four national), three health services (two national and one state-based), one national community organisation, three media agencies, five research and/or higher education organisations and one drug law reform blog. In addition to being important indicators of reach and uptake, links from other organisations build the site's credibility and authority, which in turn helps to increase its search engine ranking over time.



In the 10 week reporting period (from when the site went live to 7 December 2016) the website also attracted significant attention on social media with 987 social media referrals, the majority of which were from Facebook (68%) and Twitter (27%). In addition to the social media coverage, members of the research team also conducted two radio interviews about the project and website, one with Australia's public broadcaster, the ABC, and the other with a state-based radio station. This is part of an ongoing program to publicise the website to members of the public, including people affected by addiction issues and their family and friends.

At the time of writing, content from the site was being used at an Australian university in an undergraduate course on 'Drugs and Addiction' to facilitate discussion on narratives and counter-narratives of drug use. Plans were underway to integrate a selection of the audio recordings and video re-enactments into a Masters of Addictive Behaviours course at a second Australian institution to generate discussion on the role of stigma in the lives of people who use drugs and how to combat it.

## **Discussion**

There is a global move towards recognising the impact of research and reflecting the multiple ways in which knowledge is generated and used, beyond traditional academic measures (Greenhalgh, Raftery, Hanney, & Glover, 2016). While this research project also produced traditional academic outputs (Dilkes-Frayne, Fraser, Pienaar, & Kokanovic, 2017; Fraser et al., 2017; Moore, Pienaar, Dilkes-Frayne, & Fraser, 2017; Pienaar & Dilkes-Frayne, 2017; Pienaar et al., 2015; Pienaar et al., 2016), livesofsubstance.org was its main public output:

aimed at a wider audience and with the aim of intervening in public understandings of addiction. The question of how to evaluate these efforts is a challenging one. While evaluation methods for the content and format of specific resources provide some guidance (Hawton et al., 2012), and progress has been made in efforts to provide contextual evaluations of complex policy interventions (Pawson, Greenhalgh, Harvey, & Walshe, 2005) and the use of web-based resources in clinical trials (Eysenbach G, 2011), initiatives such as [livesofsubstance.org](http://livesofsubstance.org), which have broad social agendas, remain difficult to evaluate. This evaluation used a variety of methods to tie together information about the reach of the website, audience experience and endorsement by other relevant organisations (Neiger et al., 2012). In particular, audience experience was examined in relation to the website's specific social goals, that is, its aim not just to 'provide information' but to encourage reflection on the meaning of 'addiction' as visitors encounter experiences rarely associated with the term in public discourse.

Survey participants strongly endorsed the website's capacity to address stigma associated with addiction. The comments highlight an ongoing need to combat addiction-related stigma and incidentally make the link to reforming prohibitionist drug laws so that people can share their experiences publicly with potentially less fear of discrimination and/or the threat of legal action. These comments also highlight that people who experience addiction struggle to be accepted as authentic citizens with lives that are valued and considered 'worthy' (Fraser, 2010; Petersen, Davis, Fraser, & Lindsay, 2010). Such comments endorse the larger 'project' of [livesofsubstance.org](http://livesofsubstance.org) as a social intervention to reformulate social understandings of addiction. It remains to be seen how this website, supported by ongoing promotion and dissemination, can further affect how addiction is understood and presented in popular, health service and policy spheres.

As an additional measure of the website's impact and uptake, site analytics and information about the organisations that linked to the LoS website were also collected. Without access to comparative data for similar public information websites, it is difficult to assess these data. The early interest shown by survey participants with a professional interest indicates the promotion of the site during this period (via professional networks). Although [livesofsubstance.org](http://livesofsubstance.org) was publicly accessible, it was not easily findable as it took about five months to achieve visible ranking in Google search results. However, for a new website yet to establish its domain authority and achieve a visible search engine ranking, the data show promising indicators of the website's future performance as a reliable, authoritative online information resource. While links to the website from other organisations can be treated as a measure of impact, they are also of course a means of promoting the site and generating additional engagement. In addition, given the issues of reputation and risk management that emerge for research teams and universities when entering controversial public debate in an active way, the endorsement provided via organisational links is useful in affirming the website's credibility and legitimacy as a public information resource. Similarly, the social media metrics indicate that, not only is the website reaching its target audience of the general public, but it is being met with a positive reception as people are engaging with the content and sharing it with their online networks.

Previous evaluations of HealthTalkOnline projects have been undertaken with selected samples (that is, participants were recruited from support groups of clinics for a specific sub-study viewing and commenting on the resource in laboratory conditions and with researchers present) (Newman et al., 2009; Rozmovits & Ziebland, 2004; Sillence et al., 2003).

Compared with those previous evaluation designs, the livesofsubstance.org evaluation is relatively close to ‘real life’ use (Pawson et al., 2005). This alternative mixed-method design may lessen concerns about translation outside the laboratory setting, but raises other issues. For example, during the evaluation period, the website was not easily findable on Google as the domain was newly registered (Google favours older, established domains) (Gabrowski, 2014). This means most visitors were likely attracted to the website via direct link (e.g. on postcards, at the website launch, during presentations at conferences), sector newsletters, social media posts, email announcements and links from other websites. As a result, the survey attracted a high proportion of responses from people with a professional interest in the sector. Health professionals are an important target audience for the website, but this means the survey accessed only a low proportion of people with a personal interest in addiction issues or via an organic search (e.g. on Google). It is also possible that these constraints to survey recruitment may have encouraged responses from visitors sympathetic to the site’s aims.

## **Conclusions**

Innovative methods are required to challenge deeply rooted professional and lay assumptions about addiction. This project used rigorous research methods to develop a public-facing website to present a more nuanced and diverse range of personal stories of addiction than is otherwise available in public discourse. The responses of early website users indicate that the larger aims of the project were being achieved, the dissemination and reach of the website during its first months of operation were significant, and professional and sector support and endorsement was strong. These results indicate that the website provides a new and valued resource to contribute to the larger project of eroding addiction stigma and presenting people

who use drugs as complex individuals, with rich, varied experiences whose lives cannot be reduced to the typical addiction narrative of ruin and redemption.

Evaluating an online resource with broad aims of this kind is a challenge. Additional scholarly work developing more sophisticated and sensitive mixed methods tools for projects of this kind remains to be done. The web affords researchers and others the opportunity to add rigorous new knowledge directly into the public domain via projects like [livesofsubstance.org](http://livesofsubstance.org). Tracking the reception of such projects means reaching beyond the usual clinic populations, finding methods that do not interfere with low threshold access, mixing quantitative and qualitative data and utilising new collection techniques. Doing so is essential if we are to continue to produce resources that tackle stigma and accepted wisdom and push professional and public debate forward on important issues such as addiction.

Version accepted for publication

## References

- Ahern, J., Stuber, J., & Galea, S. (2007). Stigma, discrimination and the health of illicit drug users. *Drug and Alcohol Dependence*, 88, 188-196.
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. Retrieved from Washington DC:
- Berridge, V. (2013). *Demons: Our changing attitudes to alcohol, tobacco and drugs*. Oxford: Oxford University Press.
- Brener, L., von Hippel, W., von Hippel, C., Resnick, I., & Treloar, C. (2010). Perceptions of discriminatory treatment by staff as predictors of drug treatment completion: utility of a mixed methods approach. *Drug and Alcohol Review*, 29, 491-497.
- Carter, A., & Hall, W. (2012). *Addiction neuroethics: the promises and perils of addiction neuroscience*. Cambridge: Cambridge University Press.
- Dilkes-Frayne, E., Fraser, S., Pienaar, K., & Kokanovic, R. (2017). Iterating 'addiction': Residential relocation and the spatio-temporal production of alcohol and other drug consumption patterns. *International Journal of Drug Policy*, 44, 164-173.
- Dingel, M., Karkazis, K., & Koenig, B. (2011). Framing nicotine addiction as a "disease of the brain": Social and ethical consequences. *Social Science Quarterly*, 92(5), 1363-1388.
- Dwyer, R., & Fraser, S. (2016a). Addicting via hashtags: How is Twitter making addiction? *Contemporary Drug Problems*, 43(1), 79-97.
- Dwyer, R., & Fraser, S. (2016b). Making addictions in standardised screening and diagnostic tools. *Health Sociology Review*, 25(3), 223-229.
- Eysenbach G. (2011). CONSORT-EHEALTH: Improving and Standardizing Evaluation Reports of Web-based and Mobile Health Interventions. *Journal of Medical Internet Research*, 13(4), e126.
- Fraser, S. (2006). The chronotope of the queue: Methadone maintenance treatment and the production of time, space and subjects. *International Journal of Drug Policy*, 17, 192-202.
- Fraser, S. (2010). Hepatitis C and the limits of medicalisation and biological citizenship for people who inject drugs. *Addiction Research and Theory*, 18(5), 544-556.
- Fraser, S., & Moore, D. (2008). Dazzled by unity? Order and chaos in public discourse on illicit drug use. *Social Science and Medicine*, 66(3), 740-752.
- Fraser, S., Moore, D., & Keane, H. (2014). *Habits: Remaking addiction*. Basingstoke, UK: Palgrave Macmillan.
- Fraser, S., Pienaar, K., Dilkes-Frayne, E., Moore, D., Kokanovic, R., Treloar, C., & Dunlop, A. (2017). Addiction stigma and the biopolitics of liberal modernity: A qualitative analysis. *International Journal of Drug Policy*, 44, 192-201.
- Fraser, S., & valentine, k. (2008). *Substance and substitution: Methadone subjects in liberal societies*. Basingstoke: Palgrave Macmillan.
- Gabrowski, P. (2014). 30 most important Google ranking factors a beginner should know. Available at: <http://positiononly.com/blog/seo/google-ranking-factors>.
- Greaves, L., Poole, N., & Boyle, E. (2015). *Transforming Addiction: Gender, Trauma, Transdisciplinarity* New York/London: Routledge.
- Greenhalgh, T., Raftery, J., Hanney, S., & Glover, M. (2016). Research impact: a narrative review. *BMC Medicine*, 14, 78. doi:10.1186/s12916-016-0620-8
- Griffiths, M. (2008). The biopsychosocial and "complex" systems approach as a unified framework for addiction. *Behavioral and Brain Sciences*, 31(4), 446(442).
- Griffiths, M. (2009). A "Components" Model of Addiction within a Biopsychosocial Framework. *Journal of Substance Use*, 10(4), 191-197.
- Halkitis, P. (2009). *Methamphetamine Addiction: Biological Foundations, Psychological Factors, and Social Consequences*. Washington: APA Publications.

- Hatzenbuehler, M., Phelan, J., & Link, B. (2013). Stigma as a Fundamental Cause of Population Health Inequalities. *American Journal of Public Health, 103*, 813-821.
- Hawton, K., Sutton, L., Simkin, S., Walker, D.-M., Stacey, G., Waters, K., & Rees, S. (2012). Evaluation of a Resource for People Bereaved by Suicide. *Crisis, 33*(5), 254-264. doi:10.1027/0227-5910/a000145
- Health Experiences Research Group (HERG). (2010). *Researcher's Handbook for Producing HealthTalkOnline and YouthHealthTalk Websites*. Retrieved from Oxford:
- Holden, K. (2005). *In my skin*. Melbourne: Text Publishing.
- Kalant, H. (2009). What neurobiology cannot tell us about addiction. *Addiction, 105*, 780-789.
- Kaye, K. (2012). Demedicalizing addiction: Toward biocultural understandings. In J. Netherland (Ed.), *Critical Perspectives on Addiction* (pp. 27-52). Bingley: Emerald Group Publishing.
- Keane, H. (2002). *What's wrong with addiction?* Melbourne: Melbourne University Press.
- Kushner, H. (2010). Toward a Cultural Biology of Addiction. *BioSocieties, 5*(1), 8-24.
- Livingston, J. D., Milne, T., Fang, M. L., & Amari, E. (2012). The effectiveness of interventions for reducing stigma related to substance use disorders: a systematic review. *Addiction, 107*(1), 39-50.
- Lloyd, C. (2013). The stigmatization of problem drug users: A narrative literature review. *Drugs: Education, Prevention & Policy, 20*(2), 85-95.
- Martin, P., Weinberg, B., Bealer, B., & Martin, P. (2007). *Healing Addiction: An Integrated Pharmacopsychosocial Approach to Treatment*. Hoboken, NJ: John Wiley.
- Moore, D., Pienaar, K., Dilkes-Frayne, E., & Fraser, S. (2017). Challenging the addiction/health binary with assemblage thinking: An analysis of consumer accounts. *International Journal of Drug Policy*(44), 155-163.
- Morphett, K., Carter, A., Hall, W., & Gartner, C. (2017). Framing tobacco dependence as a "brain disease": Implications for policy and practice. *Nicotine & Tobacco Research, 19*(7), 774-780.
- Neiger, B. L., Thackeray, R., Wagenen, S. A. V., Hanson, C. L., West, J. H., Barnes, M. D., & Fagen, M. C. (2012). Use of Social Media in Health Promotion. *Health Promotion Practice, 13*(2), 159-164. doi:doi:10.1177/1524839911433467
- Netherland, J. (2011). 'We haven't sliced open anyone's brain yet': Neuroscience and the embodiment and government of addiction. In M. Pickering & I. van Keulen (Eds.), *Sociological reflections in neuroscience* (pp. 153-177). Bingley: Emerald Group.
- Newman, M. A., Ziebland, S., & Barker, K. L. (2009). Patients' views of a multimedia resource featuring experiences of rheumatoid arthritis: pilot evaluation of [www.healthtalkonline.org](http://www.healthtalkonline.org). *Health Informatics J, 15*(2), 147-159. doi:10.1177/1460458209102974
- Pawson, R., Greenhalgh, T., Harvey, G., & Walshe, K. (2005). Realist Review - a new model of systematic review designed for complex policy interventions. *Journal of Health Services Research and Policy, 10*(Suppl 1), 21-34.
- Petersen, A., Davis, M., Fraser, S., & Lindsay, J. (2010). Health living and citizenship: an overview. *Critical Public Health, 20*(4), 391-400.
- Pienaar, K., & Dilkes-Frayne, E. (2017). Telling different stories, making new realities: The ontological politics of 'addiction' biographies. *International Journal of Drug Policy, 44*, 145-154.
- Pienaar, K., Fraser, S., Kokanovic, R., Moore, D., Treloar, C., & Dunlop, A. (2015). New narratives, new selves: Complicating addiction in online alcohol and other drug resources. *Addiction Research and Theory, 23*(6), 499-509.
- Pienaar, K., Moore, D., Fraser, S., Kokanovic, R., Treloar, C., & Dilkes-Frayne, E. (2016). Diffracting addicting binaries: An analysis of personal accounts of alcohol and other drug 'addiction'. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*.
- Radcliffe, P., & Stevens, A. (2008). Are drug treatment services only for 'thieving junkie scumbags'? Drug users and the management of stigmatised identities. *Social Science and Medicine, 67*, 1065-1073.
- Room, R. (2003). The cultural framing of addiction. *Janus Head, 6*(2), 221-234.

- Room, R. (2005). Stigma, social inequality and alcohol and drug use. *Drug and Alcohol Review*, 24, 143-155.
- Room, R. (2011). Substance use disorders - a conceptual and terminological muddle. *Addiction*, 106, 879-882.
- Room, R., Hellman, M., & Stenius, K. (2015). Addiction: The dance between concept and terms. *The International Journal Of Alcohol And Drug Research*, 4(1), 27-35.
- Rozmovits, L., & Ziebland, S. (2004). What do patients with prostate or breast cancer want from an Internet site? A qualitative study of information needs. *Patient Education and Counseling*, 53(1), 57-64. doi:10.1016/s0738-3991(03)00116-2
- Seddon, T. (2007). Drugs and freedom. *Addiction Research & Theory*, 15, 333-342.
- Seear, K., & Fraser, S. (2010). Ben Cousins and the 'double life': exploring citizenship and the voluntariness/compulsivity binary through the experiences of a 'drug addicted' elite athlete. *Critical Public Health*, 20(4), 439-452.
- Sillence, E., Briggs, P., & Herxheimer, A. (2003). Personal experiences matter: what patients think about hypertension information online. *Health Information on the Internet*, 42(1), 3-5.
- Smith, C. (2010). Socio-spatial stigmatization and the contested space of addiction treatment: remapping strategies of opposition to the disorder of drugs. *Social Science and Medicine*, 70(6), 859-866.
- Tiger, R. (2015). Celebrity gossip blogs and the interactive construction of addiction. *New Media Society*, 17, 340-355.
- Tindal, C., Cook, K., & Foster, N. (2010). Theorising stigma and the experiences of injecting drug users in Australia. *Australian Journal of Primary Health*, 16, 119-125.  
doi:[http://www.publish.csiro.au/?act=view\\_file&file\\_id=PY09026.pdf](http://www.publish.csiro.au/?act=view_file&file_id=PY09026.pdf)
- Treloar, C., & Holt, M. (2006). Deficit models and divergent philosophies: Service providers' perspectives on barriers and incentives to drug treatment. *Drugs; Education, Prevention and Policy*, 13(4), 367-382.
- van Boekel, L. C., Brouwers, E. P. M., van Weeghel, J., & Garretsen, H. F. L. (2013). Stigma among health professionals towards patients with substance use disorders and its consequences for healthcare delivery: Systematic review. *Drug and Alcohol Dependence*, 131(1), 23-35.  
doi:10.1016/j.drugalcdep.2013.02.018
- Vrecko, S. (2010). Birth of a brain disease: science, the state and addiction neuropolitics. *History of Human Sciences*, 23(52), 52-67.
- Weinberg, D. (2002). On the embodiment of addiction. *Body & Society*, 8(4), 1-19.
- Weinberg, D. (2011). Sociological perspectives on addiction. *Sociology Compass*, 5, 298-310.
- World Health Organization. (1992). *The ICD-10 Classification of Diseases and Related Health Problems*. Retrieved from Geneva:



Table 1 Responses to the evaluation survey items

	N (%)
<b>I was interested in Lives of Substance because... (choose all that apply):</b>	
I want to learn more about addiction or dependence	20 (33.3%)
I want to learn more about safer drug consumption	7 (11.7%)
I'm concerned about my alcohol and other drug consumption	8 (13.3%)
I'm concerned about someone else's consumption	8 (13.3%)
I work in the alcohol and other drugs sector, health services or government	20 (33.3%)
I am a student/researcher	12 (20%)
Other (please specify)	17 (28.3%)
<b>Which parts of the website were most helpful or informative to you? (choose all that apply)</b>	
Welcome/introduction (home page)	30 (50%)
Topics (summaries of key themes with clips from interviews)	35 (58.3%)
Stories (biographies of participants and clips from their interviews)	45 (75%)
Resources and information (including links to support, advocacy and campaigning organisations)	21 (35%)
<b>This website helped me to... (choose all that apply)</b>	
Learn more about alcohol and other drug addiction or dependence	27 (45.0%)
Learn about people's experiences of self-help, treatment or changing consumption practices	35 (58.3%)
Hear/read about experiences that were new or unfamiliar to me	23 (38.3%)
Feel supported by other people's stories	14 (23.3%)
Have more confidence to talk to someone I am concerned about	3 (5.0%)
Have more confidence to talk to professionals about alcohol or other drug consumption or addiction	11 (18.3%)
Other (please specify)	9 (15.0%)

**Disclosure of interest**

No disclosures

*Version accepted for publication*