# Needles & know-how – reducing harm to those who inject drugs "It's the gift that keeps giving" A story of knowledge mobilisation, science communication & PPIE

# Why was this project started?

Supporting people to inject drugs in the least harmful way is important, as most new hepatitis C infections in the UK are amongst those who inject drugs and nearly three million people who inject drugs are living with HIV. Research suggests that low dead space injecting equipment, which have a smaller amount of space in which blood and drug is retained after use, can reduce the spread of blood borne viruses such as Hepatitis C and HIV. Studies carried out by NIHR Health Protection Research Unit in Behavioural Science and Evaluation (HPRU BSE) and Applied Research Collaboration West (ARC West) found that increasing the use of low dead space equipment with detachable needles would be acceptable to those who inject drugs and could save money. The aim of this project was to share these research findings with harm reduction charities, national policymakers and commissioners and those who inject drugs to increase the use of low dead space syringes and minimise the spread of hepatitis C and HIV.

#### Who was involved and how

Relationships between Bristol Drugs Project (BDP), a local charity working with people who inject drugs, and researchers based at the University of Bristol had already been established on previous projects. In the summer of 2017, a dynamic stakeholder event was held attended by BDP service users, BDP staff, local authorities and commissioners, researchers, public health experts and injecting equipment suppliers to discuss how to disseminate and act on emerging research findings about low dead space syringes. They decided to create and distribute materials, aimed at raising awareness of low dead space syringes and other harm reduction messages amongst service users, staff and volunteers working in needle and syringe programmes and commissioners.

To help make this happen, Deb, a BDP Assertive Engagement worker, was seconded to ARC West for three days a week for eight months, funded by University of Bristol's ESRC Impact Acceleration Account. Working closely with Jo, a jointly funded HPRU / ARC qualitative researcher, they visited drug services across England, Wales and Scotland to identify local issues and the needs of the services and their population. This fact-finding mission helped Deb and Jo develop a set of key messages, with input from Zoe, ARC West's communications lead. It also gave them a clearer picture of the types of materials that would be suitable and usable for needle exchanges to share with their service users.

With a better understanding of the national picture, they put out a tender to commission a designer to bring the materials to life. They appointed Michael Linnell, an artist and graphic designer who was keen on service user involvement, to design the awareness-raising materials. Michael had a strong track record of developing materials for public health campaigns related to recreational drug use. Michael, along with Jo, Deb and Zoe, met with five BDP service users on three occasions. From these meetings, they co-produced seven <u>posters</u>, a <u>booklet</u> and a series of short <u>animations</u>, refining the messages, language and designs following each round of feedback. These materials are all available on the Exchange Supplies <u>website</u>, a social enterprise that developed detachable LDSS equipment and collaborated throughout the project.

The materials were launched with an exhibition and event in Bristol during January 2019. Some service users who were part of the project spoke about their experiences, demonstrating their commitment to and sense of ownership of the work.

To further the dissemination of these materials and make international links, Deb attended an International Harm Reduction Conference in Portugal in April 2019 with funding from the ESRC Impact Acceleration Award. Here, she met Dr William Zule, a leader of research in this field, and gave sets of the posters to those from all over the world including Scandinavia, Asia and Europe.

In addition, Deb and Jo attended the UK National Needle Exchange Forum. This provided access to other harm reduction services that Deb had not visited. From these conversations, Deb and Jo realised some needle exchange workers felt unprepared in switching to low dead space syringes. Exchange Supplies were developing some online training, which Deb then contributed to in filling this skills gap. The first level for pharmacists was co-developed by Dr Jenny Scott, pharmacist and Senior Lecturer at Bath University, it includes links to co-designed materials and has received excellent feedback. Levels 2 & 3 for drugs workers are in production.

# What difference did it make?

Awareness raising is often the first step. There is ample evidence that this project has been highly effective with multiple audiences, for example:

- The materials have received great feedback since their launch. In the three-months following the launch, there were nearly 3000 views on the Exchange Supplies website and 5000 views on Facebook, suggesting widespread reach. The posters are on display in a Safe Consumption Facility in Scotland, and Deb has also been asked to help with the design of further harm reduction materials because our materials were viewed so positively.
- The posters were spotted in the background of a social media forum post of a man in Spain. Other users of the forum then began asking for information on the source of the posters. This suggests that the messages of the posters both resonant with those who inject drugs and are spreading internationally.
- To target the scientific community, several academic papers have been written, some co-written by Deb and by the service users who co-designed the materials.
- For policymakers, a policy briefing was launched at a webinar to coincide with the United Nations 'International Day against Drug abuse and Illicit Trafficking'. 43 people attended, including the Public Health England lead for Hepatitis C prevention who wants to implement low dead space syringe procurement across England, thereby spreading the impact of the project.
- Findings from the research contributed to the NICE surveillance proposal consultation on Needle and Syringe programmes (NICE guideline PH52).

Knowledge mobilisation projects affect relationships, skills, services and eventually whole systems. Strengthened relationships are often a key marker of success, in this case between BDP, the researchers, services users and needle exchange suppliers. For example, BDP are proud of their contribution to this project and are currently hosting several new studies, further building on the relationships fostered during the low dead space project. Detachable low dead space injecting equipment has been available to needle and syringe programmes from Exchange Supplies since the start of the project and Frontier (another injecting equipment supplier) have now developed their own LDSS. With the launch of online training, skills in implementing low dead space syringe usage will spread across the country. This combination of skills training and services to support the transition to low dead space syringes should result in widespread behavioural change. This is already evident in Bristol. Using implementation strategies identified in the earlier research, BDP switched to offering low dead space injecting equipment. This transition has been smoother than any other previous equipment change because drugs workers knew the key messages to highlight. Consequently, BDP received minimal complaints. All high dead space injecting equipment has now been replaced with low dead space at BDP unless no low dead space equivalent exists. This is the change needed across the country. With the recent interest of Public Health England's lead for hepatitis C prevention and the NHS England Hepatitis C Elimination Programme, this aspiration could become a reality.

#### Why did it work?

This creative and inspiring project has been successful for several reasons.

- Good relationships between the key partners were in place early on before the research project began e.g. Bristol Drugs Project, service users, applied health researchers, public health, council commissioners and the social enterprise that supplies injecting equipment. A steering group with members from these different backgrounds was instrumental in keeping the project on course.
- A highly capable, knowledgeable, enthusiastic frontline service worker was seconded to work within a research institution as a knowledge mobiliser. Her time was ring-fenced with university impact funds and was properly resourced. She bridged the gap between researchers, service users, the charity (BDP) and the injecting equipment suppliers (Exchange Supplies). Her know-how was essential.
- 3. The excellent relationship between the knowledge mobiliser (Deb) and the main qualitative researcher (Jo) was key. Both learnt a tremendous amount from each other. The researcher supplied knowledge of research processes and opportunities to reflect and was also given the opportunity to attend service provider training on safer injecting at the start of the research project to better understand the context of the research. The knowledge mobiliser had the passion and contacts amongst drugs workers and service users. Both were able to work creatively and flexibly as the context changed, and they learnt to move outside their respective comfort zones.
- 4. **BDP managers and staff have been highly supportive**. They encouraged the frontline drugs worker to apply for the university post, proudly display six-foot versions of the posters in the public rooms of their building and continue to support the frontline drugs worker in research-related activities. They have **capitalised on her new skills and learning**,
- 5. The **service user input was key**. Without service users as co-designers, the materials would have been very different and likely ineffective at communicating and engaging with the audience.
- 6. **Communication outside normal academic channels** was a key element of this project's success. Creating the materials was in essence a design project, so the team could draw on the experience and expertise of the ARC West communications lead in commissioning this kind of work, developing key messages and fine-tuning copy. The team also benefited from the existing communications channels at ARC West, HPRU BSE, BDP and Exchange Supplies to promote the work, for example through websites, Twitter and YouTube.
- 7. The project has **consistently drawn on the know-how and networks of those they want to influence by creating mutually rewarding partnerships**. For example, service users co-designed the posters, booklet and animations; a pharmacist co-designed the training course for pharmacists. What's more, they **partnered with the right people at the right time** e.g. a social enterprise to supply the injecting equipment, an artist / graphic designer to develop the materials.

# What difference did it make on those involved?

Like most knowledge mobilisation projects, this one has had a powerful impact on those most closely involved. For example, Deb now uses Twitter extensively in a professional capacity, which has increased her profile and spread news of the project internationally. She has appeared on television and radio several times. Her role within BDP has changed, as her knowledge of research and other drugs services is valuable to her colleagues. As Deb said, *"It's the best thing I've ever done…..I can't tell you how much this has changed me…..It's given me far more confidence in my abilities."* 

Jo reflects that "Working with Deb and BDP on this project had an immense impact on me, it inspired my interest in harm reduction research and made me seriously committed to building a long-term career in addiction science. Conducting participatory research with BDP continues to motivate me to co-produce qualitative evidence which gives a voice to and values the experience of people who inject drugs so as to support drug services to continue and enhance their excellent work. I now feel like an honorary member of the BDP family, they actively support me to understand their work and the lives of those they support. This connection enables me to identify research topics of local priority."

Zoe says "I'm very proud of the work we did with the BDP service users. It's rare to work so closely with the people communications are intended for. Working like this with the end users meant that we have produced materials that we can be sure resonate with their intended audience. It's every communications professional's dream!"

Written by Lesley Wye and Clare Thomas

With thanks to Deb Hussey, Jo Kesten, Zoe Trinder Widdess and Sabi Redwood November 2020

Proposal submitted to CLAHRC West funding call, arising from the Addiction
Health Integration Team, led by Matt Hickman, and involving BDP, Bristol City
Council and the HPRU.
Qualitative study to explore PWID attitudes and preferences around injecting
equipment and identify what educational or behavioural interventions might be
needed to support increase use of low dead space
Findings of qualitative study published online. Recommendations for how to
implement the switch from HDSS to LDSS fed back to BDP
BDP implement LDSS within their service
Dynamic stakeholder event, funded by PolicyBristol, to bring together BDP
service users, BDP staff, local authorities and commissioners, researchers, public
health experts and injecting equipment suppliers. Aim was to discuss how to
support role out of LDSS more widely. Idea of scoping exercise with NSPs and
design of educational materials was put forward but funding was needed.
ESRC Impact Accelerator Award funding obtained. Deb Hussey appointed and
seconded into ARC west. Visits to NSPs and co-design project carried out.
Co-designed materials – launch event and dissemination to stakeholders.
Available to download from Exchange Supplies' website.
Deb attended International Harm Reduction Conference
Co-designed materials paper published

#### Timeline

June 2020	PolicyBristol policy report published and reported at the PolicyBristol webinar,
	leading to meeting with PHE Hep C elimination lead.
July 2020	Exchange Supplies' Online harm reduction training for pharmacy-based NSPs is
	launched, including reference to research.