

# Integrating hepatitis research and services into current care: Lessons from implementing team

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In 2016, a consortium of partners initiated a national cross-sectional study on viral hepatitis B and C among high-risk populations in South Africa. Counselling, prevention, testing and referral services were integrated into programmes that were already implementing HIV prevention services to the included populations. After study completion, we undertook a process of reflecting on challenges and lessons learned from the perspective of the service provision team. In this article, we highlight three key takeaways: additional activities can have exponential increases in workload; insufficient inclusion of service providers at planning stages has multiple long-term costs; and having to repeatedly relay infectious disease diagnoses to service users can carry an emotional toll for service providers.

*South Afr J Pub Health* 2020;4(2):47-49. <https://doi.org/10.7196/SHS.2020.v4.i2.102>

Despite a notable burden of viral hepatitis B and C (HBV and HCV), South Africa (SA) has a very limited viral hepatitis response.<sup>[1]</sup> There is no routine screening in high-risk populations, and HCV treatment is limited to selected tertiary hospitals. HBV treatment is available at primary care level but is not widely accessed, and there is little public knowledge or information available to those who are at high risk. The national management guidelines and action plan have only just been released.<sup>[1]</sup> Hepatitis care, especially for high-risk populations, should ideally be integrated into other care provision processes.<sup>[2]</sup> The literature details the impact of integrated care on vulnerable people affected by hepatitis,<sup>[3,4]</sup> but the impact on service delivery staff of integrating hepatitis services into already existing programmes is poorly documented.

In 2016, a consortium of partners initiated a national cross-sectional study on HBV and HCV among high-risk populations in SA: people who use drugs; sex workers; and men who have sex with men.<sup>[5]</sup> Counselling, prevention, testing and referral services were integrated into 11 programmes that were already implementing HIV prevention interventions in 7 cities, with 3 438 participants recruited between August 2016 and October 2017. Service delivery staff who implemented the study were experienced with the target populations, but largely unaccustomed to conducting research projects and unfamiliar with viral hepatitis. The study outcomes have raised the profile of hepatitis in SA, shaped national hepatitis

policy, drawn attention to the high seroprevalence of HCV in people who inject drugs (55% (513/937))<sup>[5,6]</sup> and illustrated linkages to care challenges for the included populations. In this article, we highlight three key service delivery team takeaways from the process: additional activities can cause exponential increases in workload; insufficient inclusion of service providers at planning stages have multiple long-term costs; and infectious disease diagnoses carry an emotional toll for service providers.

After the project, we implemented processes reflecting on challenges and lessons learned. These included a facilitated day-long workshop with 9 of the 11 site leads in which we mapped out challenges and solutions to project implementation, along with potential representative case studies. This was followed by the selection and development of detailed case studies on each of the challenges raised by project teams. The data gathered in these processes were then analysed thematically with the support of management team members, and grouped into the three key issues previously mentioned. These were reviewed and refined by site teams.

## Three key lessons

### Additional activities can cause exponential increases in workload

Cities in which the study was integrated into services provided by mobile clinics show that the integration of new services into

existing structures result in workload increases beyond the work of the newly added services. Prior to the study implementation, the mobile clinics providing harm-reduction services had set routes carefully planned for optimal service delivery and maximum reach in order to obtain funder-driven targets. The study counselling and testing processes required more time per interaction than any of the services previously offered. Consequently, implementation meant that mobile clinics had to stay in one location longer than previously, disrupting timetables and routes. These disruptions meant that we struggled to find people to provide them with services, such as sterile injecting equipment during routine outreach processes. To maintain our targets and supply the other provisions that our service users required, we extended our working hours and also rushed between sites, not stopping to fill out our documentation as we usually would have done. As a result, we had to fill out documentation after hours. This further extended the working day, and compromised data quality, which in turn caused extra work as we were required to return to documents at a later point to correct errors.

### **Insufficient inclusion of service providers at planning stages involves multiple long-term costs**

The structure of proposal writing, project planning and grant-seeking is such that it is easy for researchers and project managers to treat service delivery teams as implementing partners, but not planning and management partners. Yet service providers have intimate knowledge of the population served, the structure of day-to-day activities and the requirements of projects, processes and funders already in place. Where they are not fully included in planning, it can cause conflict of interest, and involves long-term costs for the participants, research quality and service providers themselves. In our project this manifested in a number of ways, including misaligned allocations of time, money, commodities and skills. It also resulted in suboptimal service provision and – sometimes – strained relations between service providers and users, something particularly evident in the referrals of people who tested positive for hepatitis. In Cape Town, the referral process set up by the management team seemed straightforward: the study site was to communicate with the specialist Liver Clinic, request an appointment date for the patient and pass on the results from laboratory assessments to the clinic. The Liver Clinic then set a date for the patient, and communicated it to the service delivery organisation, which passed the information on to the patient, who was then expected to attend the service themselves. As service providers we were unaware – and did not relay to service users – that the first visit to the Liver Clinic was not to see a hepatologist or get any clear answers, but rather to draw bloods, something we could have done ourselves. Service users attending their first appointment expressed their disappointment and anger at us for not providing them with this information, or drawing bloods ourselves to streamline the process. In one case this resulted in a client refusing to access routine services, resulting in the discontinuation of chronic medication access for a

few months. In the end, <1% of people referred for follow-up appointments attended them. We suggest that our early involvement in planning could have foreseen some key referral pathway difficulties, and aligned research and implementation needs in ways that consistently strengthened, rather than challenged, our relationships with service users.

### **Infectious disease diagnoses carry an emotional toll for service providers and users alike, and adding an additional infectious disease service can result in staff distress and compassion fatigue**

As implementing teams working with HIV, we already carry the burden of informing people when they are HIV-positive. Viral hepatitis is more difficult in that there is very little public knowledge about it, and treatment (for HCV) and/or management (for HBV and HCV) is more complicated, and less readily available. This burden was experienced particularly by the team providing services to people who inject drugs in Pretoria, where 84% of the 320 people who inject drugs recruited for the study tested positive for HCV on a point-of-care test. In Pretoria, unlike Cape Town, HCV treatment was not available from the public healthcare system. This meant that the small team of counsellors and nurses had to tell 270 people that they likely had chronic hepatitis, a potentially deadly disease, and the only form of consolidation was a referral letter to the nearest hospital (reputed to stigmatise people who inject drugs) where their liver functions could be assessed. The emotional toll was huge on both the affected participants and the study staff, who reported suffering exhaustion, feelings of helplessness and distress, compassion fatigue, reduced motivation and strained relationships within the staff team.

### **Recommendations**

To lend our experience to future projects seeking to integrate research and implementation into current services, we highlight three recommendations related to the points we have raised above.

#### **Use mini-pilot processes to test out real requirements and impacts of integrating additional services**

It is difficult to anticipate the ways in which new services will impact those already in place unless pilot processes are conducted by implementing teams prior to standard operating procedure finalisation. Piloting should include running through every action required by the added service within the current system, and should be used to assess how and why workload increases occur, to inform adapted, streamlined processes, to support budget allocations and to highlight training gaps.

#### **Service delivery staff must be engaged as equal knowledge partners, recognising and harnessing their deep knowledge of the people they serve and the context they work in**

This factor should include true collaboration in every aspect of project planning and implementation from the outset. In order

to ensure this is carried through, a collaboration process should be agreed to at the outset, and accountability processes set up to respond to and manage inclusion failures. While this may increase planning costs and time, we suggest that these should be considered in light of the reduction of costs for those implementing service delivery during the implementation period and likely expedited enrolment period.

### Seek to reduce the emotional toll on service providers of providing positive diagnoses and counselling

A first step in this goal is ensuring adequate after-care options for service users, including provisions for psychosocial support and peer-navigated linkages to care and treatment. Furthermore, projects should seek to ensure that there are psychosocial support services for implementing teams, such as regular, scheduled debriefing or counselling. Projects could also build in the option of staff rotating to another work area for recuperation periods.

### Conclusion

Large-scale treatment and care of people with chronic hepatitis will require a new public health approach to service delivery that includes integrated, decentralised care. This will require changes to current services, and that implementing staff – the most important resource in any healthcare system – are taken into account. Here we have suggested that three key ways in which this should be done are through piloting of planned processes, true inclusion at all levels of decision-making and through seeking to minimise the emotional toll of adding a further infectious disease to the workload. Without these steps, integrating services risks compromising the quality of care provided to patients, and the quality of life and work of the people implementing the care.

**Acknowledgements.** The authors would like to acknowledge all their colleagues with whom they implemented the Bristol-Myers Squibb Foundation Viral Hepatitis Initiative, as well as all participants in the study. Further thanks to TB HIV Care for leading and hosting the study.

**Author contributions.** All authors participated in the reflection process, were involved in the development and writing of case studies, approved the data analysis outcomes and were involved in developing, commenting on and reviewing the final manuscript.

**Funding.** This reflection process was not funded, but it did draw on parent study funding received from the Bristol-Myers Squibb Foundation. The funder was not involved in the design of the study, or the collection, analysis or interpretation of data.

**Conflicts of interest.** None.

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*Accepted 17 December 2019.*