

The PROgress Study

An electronic solution for improving patient consultation visits in routine HIV care

HIV therapy has been a spectacular success over the past 30 years, transforming a disease that was once considered a life sentence into a manageable, chronic condition. With treatments so effective, clinical focus has now changed to looking at ways of improving patients' quality of life. Understanding each individual's unique situation is key yet this presents a challenge for care providers within time-constrained patient visits. Duncan Short, PhD, of Viiv Healthcare and the PROgress Study team have demonstrated the value of a simple but highly effective pre-consultation electronic questionnaire to help people living with HIV share their story and play a significant role in their own wellbeing.

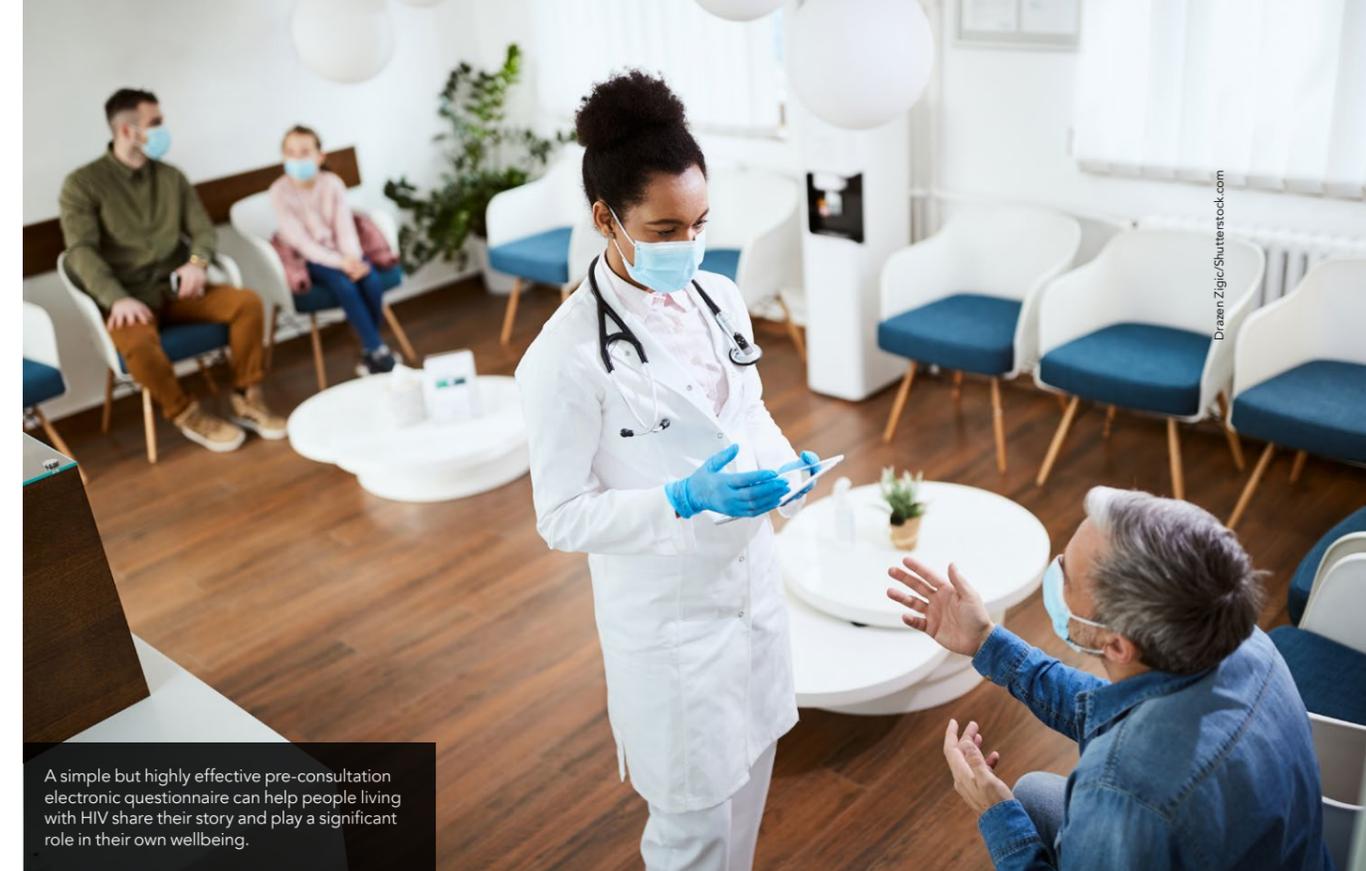
It is an inconvenient truth of healthcare that no two patients are the same. This is especially relevant when it comes to optimising the care of people living with HIV (PLHIV). New medicines have made it possible for PLHIV to live as long as those without the virus, but HIV is still heavily stigmatised and can impact individuals in multiple complex ways. For those entrusted with providing healthcare, knowing those details holds tremendous relevance and value for decision making that impacts their patients' health and wellbeing. Yet it is all too common that key elements of individuals' lives are not shared, individuals aren't fully understood, and care opportunities are missed. PLHIV may feel sensitive or uncomfortable proactively discussing topics such as mental health, drug use, poverty, or physical abuse, and care providers may not have the time to ask in short appointments. So what would happen

if we could find an easy way, using everyday technology, for those stories to be told?

Dr Duncan Short is Director of Global Implementation Science at Viiv Healthcare, a London-based pharmaceutical company that is 100% dedicated to discovering and developing medicines for HIV treatment, prevention and cure. One of his responsibilities is leading the PROgress Project – a workstream to investigate whether a pre-consultation electronic tablet-based survey provided in the waiting room of an HIV clinic can provide valuable real-time insights to improve routine patient care. This may sound like a logical precept, but it is not without its difficulties. These include logistical implications for clinics to integrate this within clinic flow and acceptability challenges for both patients and care providers.

THE CHALLENGES OF PATIENT-REPORTED OUTCOMES (PROs)

Core to Short's recent study is the concept of a patient-reported outcome (PRO) – information provided by a patient on their health condition that is not directed or explained by someone else, such as a healthcare professional. Formal PROs typically take the form of a questionnaire that touch on such aspects as a person's mental health, social wellbeing, symptoms, health behaviours, and medication challenges. PROs are common valuable components in clinical trials, but they are used less so in direct patient-clinician appointments for several reasons. Firstly, form-filling takes time and effort on behalf of patients, and secondly, processing and analysing the assessments generate an extra administrative workload for busy clinic staff. In an HIV clinic, the



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face-to-face time between clinician and patient is frustratingly brief for both. However, the information patients can offer through PROs could be vital to the care they receive from their healthcare team. Hence the value of PRO assessment information to unlock the best support for an individual. So, the team wondered if there could be a way to create and integrate an easy-to-use, data-rich – but succinct – pre-consultation electronic PRO tool to help clinical staff in different types of clinics that could be adopted within routine HIV care at scale.

Working with the University of Washington's Center for AIDS Research in Seattle, Washington, USA, and under the guidance of a steering committee that included PLHIV, clinic directors, HIV care providers, and healthcare researchers, the team tested a self-administered electronic tablet-based PRO assessment which was quick and effective. They were helped by two very different outpatient clinics: one within

St Michael's Hospital (SMH) in Toronto, Ontario, Canada; the other, the Midway Specialty Care Center (MSCC) in Fort Pierce, Florida, in the US. The two clinics also served different population needs and challenges. The study team's concerns: was such a PRO intervention feasible within routine practice, and would it be valuable?

A SIMPLE BUT THOROUGH DESIGN

The study was conducted at the two clinics between August 2018 and July 2020. Patients selected for the study were HIV positive and attending a routine visit at either clinic. They also had to understand any of the three languages in which the assessment had been designed: English, Spanish, or Haitian Creole. Patients were presented with the tablet device in the waiting room with a brief explanation of how to use it and the purpose of the PRO assessment. The PRO questions differed slightly between the two clinics and were primarily designed to provide critical information about such issues

as patients' adherence to their HIV medications; smoking, alcohol and substance use; intimate partner violence; housing and living conditions and, importantly, possible healthcare issues such as anxiety, depression, and suicidal ideation. That's a lot of information, and if the assessment were in a traditional paper format it would be daunting for any patient to engage with and for the clinics to interpret.

This is where the use of an electronic tablet format was a masterstroke. The assessment's simple but thorough design and the tablet's ease of use made it an engaging and interactive tool. Of the 1,813 eligible patients presented with the tablet while waiting for their clinic appointment, 90% agreed to participate. Reasons for not engaging with the assessment usually centred around literacy, language, or visual barriers – they couldn't read or speak one of the assessment's languages or didn't have their glasses. Incredibly, all but two of the 1,632 patients who





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started assessment completed the entire set. Such an enthusiastic and thorough engagement with a PRO assessment in a clinic environment is a favourable outcome in itself.

THE STANDOUT SUCCESSES

The assessment wouldn't help a clinic's healthcare staff if it flooded them with data they had to wade through. Instead, the electronic PRO produced a concise one-page assessment summary with critical information the clinic needed on each patient – a brief but highly valuable snapshot. Importantly, it helped to uncover otherwise hidden patient needs and behaviours. This was one of the standout successes of

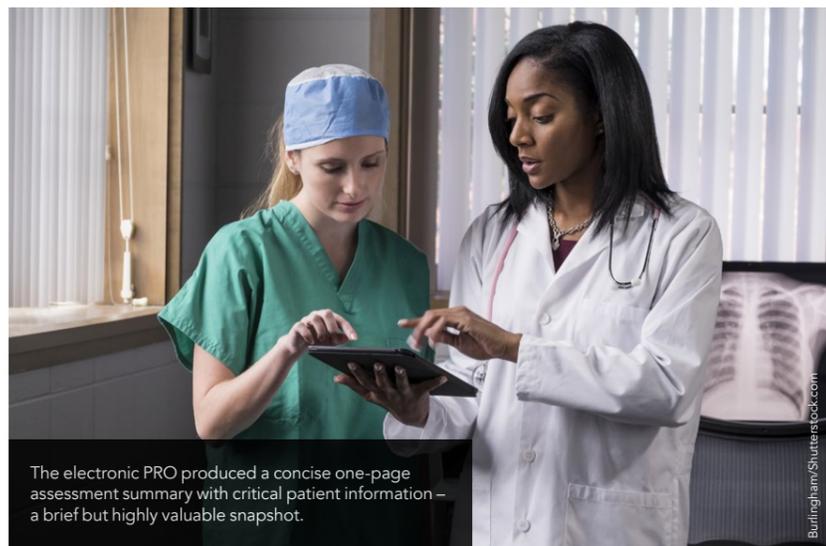
the PROgress Project. For example, it pointed towards any serious or developing mental health issues – something easily missed in the short time of a typical routine appointment – that the clinician could address. An HIV patient's mental state of health is a key determinant in their overall wellbeing and the potential effectiveness of the treatment they receive.

But there was more to the study than demonstrating patient uptake of the assessment and the generation of data. The study team showed how and why a properly designed PRO assessment is highly valued. It improved clinicians' awareness and monitoring of patient

needs, behaviours, and health issues. It also enhanced clinician and patient communication – with more information at hand, clinicians engaged in a more focussed manner with patients. Equally importantly, all this was integrated into routine care with minimal disruption to clinic operations. Highly acceptable by all users, PROs improved the clinic experience for patients and made the consultation easier for healthcare providers.

Alongside the research, the team have also developed the [PROgress Implementation Toolkit](#) as a resource for healthcare providers, offering practical advice on the implementation of PROs in routine HIV care in their clinic.

The PROgress study stands out in the realm of current HIV research for several reasons. As the focus in HIV care shifts towards overall patient wellbeing and health-related quality of life as treatment outcome targets, the patients themselves – not just the interventions per se – are critical in determining the outcome success. Therefore, using PRO in routine HIV care is a development worth supporting and exploring further. Something that produces remarkable uptake in patient engagement and supports improved patient-provider information exchange, with minimal disruption to clinic operations, is worth celebrating.



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Behind the Research

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Research Objectives

The PROgress Study explored the added value of introducing patient reported outcomes (PROs) in routine HIV care, and implementation of best practice.

Detail

Bio

Dr Duncan Short is Director of Global Implementation Science at ViiV Healthcare.

Funding

The research was funded by ViiV Healthcare, a specialist pharmaceutical company 100% dedicated to the discovery and development of HIV medicines for treatment, prevention and cure.

Collaborators

- University of Washington, Seattle, USA
- Ontario HIV Treatment Network, Canada
- St Michael's Hospital, Toronto, Ontario, Canada
- Midway Specialty Care Center, Fort Pierce, Florida, USA
- PROgress Study Steering Group



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Personal Response

What do you hope the impact of your research will be?

“ The focus of HIV clinical care has firmly shifted beyond viral suppression. Treatment outcome targets now also include positive patient wellbeing and health-related quality of life. This study has shown how a well-implemented PRO assessment process before the patient and the healthcare provider meet can play an important part in helping providers understand the individuals they care for and therefore meet their evolving needs. The study and our implementation toolkit will hopefully help those wanting to introduce PROs into their practice to take that first step to improving patient care. ”