# Reminder systems for people living with HIV

## **?** Questions

- What types of telephone, computer and other app-based interventions have been effective in reminding people living with HIV to attend medical appointments and adhere to antiretroviral medications?
- What types of telephone, computer and other app-based interventions have been effective in reminding people living with HIV to test/retest for STIs and subsequently notify their partners when testing positive?

### Key Take-Home Messages

- Text messaging, smart phone applications and cell phone counselling are all effective in promoting adherence to antiretroviral therapy (1-4).
- Text messaging and smart phone reminders are more effective if they are personal in nature, and if they evoke or require a response from the participant (2;4-6).
- Text and telephone reminders have shown limited ability to improve clinic appointment attendance (7;8). One automated telephone reminder service did, however, improve attendance but only in patients who were stably housed, not depressed and attending five or more appointments within a six-month period (9).
- Text messaging and email reminders have proven effective in promoting STI retesting among high risk groups (10;11); however, these results have not been consistent (Burton).
- While text message and email notifications may not be sufficient on their own for the purposes of partner notification, they may be useful when used in conjunction with traditional notification systems (12;13).

## The Issue and Why It's Important

The introduction of antiretroviral therapy (ART) has transformed HIV into a chronic, manageable condition; however, treatment is only effective with stringent adherence to ART regimens (4). Significant numbers of people receiving ART have incomplete viral suppression and require more assistance with adherence than is

### References

1. Belzer ME, Naar-King S, Olson J, Sarr M, Thornton S, Kahana SY et al. The use of cell phone support for non-adherent HIV-infected youth and young adults: an initial randomized and controlled intervention trial. AIDS & Behavior 2014 April;18(4):686-96.

2. Finitsis DJ, Pellowski JA, Johnson BT. Text message intervention designs to promote adherence to antiretroviral therapy (ART): a meta-analysis of randomized controlled trials. PLoS ONE [Electronic Resource] 2014;9(2):e88166.

3. Kalichman SC, Kalichman MO, Cherry C, Swetzes C, Amaral CM, White D et al. Brief behavioral self-regulation counseling for HIV treatment adherence delivered by cell phone: an initial test of concept trial. AIDS Patient Care & Stds 2011 May;25(5):303-10.

4. Perera AI, Thomas MG, Moore JO, Faasse K, Petrie KJ. Effect of a smartphone application incorporating personalized health-related imagery on adherence to antiretroviral therapy: a randomized clinical trial. AIDS Patient Care & Stds 2014 November;28(11):579-86. possible with routine clinic visits (3). In addition, patients who live in less urban areas have fewer clinical contacts and are in need of even greater support to ensure proper ART adherence (3).

Follow-up appointments with HIV physicians and monitoring are essential components of HIV management and treatment. Patients on ART should be monitored regularly and have viral load, CD4, blood lipids, glucose and liver and kidney function tests performed routinely. Appointment no-shows have been associated with poor ART adherence, delayed monitoring, progression to AIDS, ART resistance and increased mortality (9).

Telephone, computer and other app-based interventions could also prove useful in relation to partner notification and STI retesting. These new means of communication could encourage people newly diagnosed with HIV to confidentially notify their previous sexual partners (13). They could also encourage people living with HIV to routinely retest for sexually transmitted infections if they are a member of a high-risk group and have been previously diagnosed with an STI (14).

### 💵 What We Found

Overall acceptability of cell phone and text

message reminders

In a 2011 U.S. study, Person et al. used anonymous surveys to assess attitudes towards healthcare-related cell phone use and text messaging among people at risk or infected with tuberculosis or HIV. Of 315 survey respondents:

- 77% (n=241) owned cellphones.
- 56% felt it would be acceptable to receive appointment reminders, while 14% were unsure of the acceptability and 30% felt that it was unacceptable.
- 33% felt it was acceptable to receive text message reminders for medication adherence, 17% were unsure of its acceptability, while 43% felt it was unacceptable.
- Younger age and owning a cell phone were associated with positive attitudes towards receiving appointment reminders, while only younger age was associated with acceptability of medication reminders (15).

Types of reminder services

### a) Reminders for increasing HIV clinic appointment attendance

Two interventions among clinic-based populations did not find text

5. Hailey JH, Arscott J. Using technology to effectively engage adolescents and young adults into care: STAR TRACK Adherence Program. Journal of the Association of Nurses in AIDS Care 2013 November;24(6):582-6.

6. Lewis MA, Uhrig JD, Bann CM, Harris JL, Furberg RD, Coomes C et al. Tailored text messaging intervention for HIV adherence: a proof-ofconcept study. Health Psychology 2013 March;32(3):248-53.

7. Farmer T, Brook G, McSorley J, Murphy S, Mohamed A. Using short message service text reminders to reduce 'did not attend' rates in sexual health and HIV appointment clinics. International Journal of STD & AIDS 2014 March;25(4):289-93.

8. Perron NJ, Dao MD, Kossovsky MP, Miserez V, Chuard C, Calmy A et al. Reduction of missed appointments at an urban primary care clinic: a randomised controlled study. BMC Family Practice 2010;11:79.

9. Henry SR, Goetz MB, Asch SM. The effect of automated telephone appointment reminders on HIV primary care no-shows by veterans. Journal of the Association of Nurses in AIDS Care 2012 September;23(5):409-18.

10. Bourne C, Knight V, Guy R, Wand H, Lu H, McNulty A. Short message service reminder intervention doubles sexually transmitted infection/HIV re-testing rates among men who have sex with men. Sexually Transmitted Infections 2011 April;87(3):229-31.

11. Zou H, Fairley CK, Guy R, Bilardi J, Bradshaw CS, Garland SM et al. Automated, computer generated reminders and increased detection of gonorrhoea, chlamydia and syphilis in men who have sex with men. PLoS ONE [Electronic Resource] 2013;8(4):e61972. messages and telephone reminder systems effective in increasing HIV clinic appointment attendance.

- A study by Farmer et al. (2014) conducted in London, UK, compared no attendance and cancellation rates for two 12-month periods before and after the introduction of a text message for patients with pre-booked appointments. There were no significant changes in HIV clinic attendance rates between groups (7).
- Perron et al. (2010) conducted a randomized controlled study in Geneva, Switzerland in which clinic patients were first called or sent a text message reminder, or finally sent a reminder by mail. The intervention failed to decrease the number of missed appointments (8).

A third study (Henry et al. 2012) examined the effectiveness of adding an automated telephone reminder to improve appointment attendance for HIV-positive patients in Los Angeles. The study showed that the intervention was effective for patients who were not homeless, not diagnosed with depression, or had five or more appointments scheduled in six months. The intervention was not effective in increasing attendance among patients who were homeless, from ethnoracial minorities or had mental health issues (9).

Overall, there is a lack of evidence supporting text message and telephone reminders as a tool to increase HIV clinic appointment attendance.

### b) Reminders for STI retesting among high risk groups

Two studies found that reminder technologies were effective in increasing STI retesting rates among men who have sex with men (MSM).

- An Australian study by Zou et al. (2013) examined the impact of automated text messaging and email reminders generated by computer assisted self-interview to remind MSM to retest for STIs. Men who chose three or six monthly reminders visited the clinic more than those in the control group. Men receiving reminders were also more likely to test for at least one or a combination of STIs during the same visit compared to men in the control group. Men receiving reminders had a higher detection rate for rectal gonorrhea, chlamydia and early latent syphilis, demonstrating that this type of reminder systems is associated with increased detection of bacterial STIs in MSM (11).
- A study by Bourne et al. (2011) also conducted in Australia evaluated the impact of a text message reminder system for HIV/STI retesting among MSM. After nine months, in the text message group, 64% were retested compared to 30% in the

12. Gotz HM, van Rooijen MS, Vriens P, Op de CE, Hamers M, Heijman T et al. Initial evaluation of use of an online partner notification tool for STI, called 'suggest a test': a cross sectional pilot study. Sexually Transmitted Infections 2014 May;90(3):195-200.

13. Hightow-Weidman L, Beagle S, Pike E, Kuruc J, Leone P, Mobley V et al. "No one's at home and they won't pick up the phone": using the Internet and text messaging to enhance partner services in North Carolina. Sexually Transmitted Diseases 2014 February;41(2):143-8.

14. Burton J, Brook G, McSorley J, Murphy S. The utility of short message service (SMS) texts to remind patients at higher risk of STIs and HIV to reattend for testing: a controlled before and after study. Sexually Transmitted Infections 2014 February;90(1):11-3.

15. Person AK, Blain ML, Jiang H, Rasmussen PW, Stout JE. Text messaging for enhancement of testing and treatment for tuberculosis, human immunodeficiency virus, and syphilis: a survey of attitudes toward cellular phones and healthcare. Telemedicine Journal & E-Health 2011 April;17(3):189-95.

16. Dowshen N, Kuhns LM, Johnson A, Holoyda BJ, Garofalo R. Improving adherence to antiretroviral therapy for youth living with HIV/AIDS: a pilot study using personalized, interactive, daily text message reminders. Journal of Medical Internet Research 2012;14(2):e51.

17. Robbins GK, Testa MA, Su M, Safren SA, Morse G, Lammert S et al. Site nurse-initiated adherence and symptom support telephone calls for HIV-positive individuals starting antiretroviral therapy, ACTG 5031: substudy of ACTG 384. HIV Clinical Trials 2013 September;14(5):235-53.

control group and 31% in the pre-text message group. When baseline differences were adjusted, men in the text message group were four times more likely to retest than men in the comparison group (10).

However, another study found that text message reminders did not increase retesting rates. A UK study by Burton et al. (2014) measured the impact of text message reminders on the re-attendance rate of patients who require repeat STI testing and found no difference in attendance rates between the texting group and the control group (14). High rates of STIs were found in patients in both groups, and rates were particularly high if the reason for recall was chlamydia infection at the initial visit.

### c) Reminders for STI partner notification

Two studies tested the use of reminder technologies to encourage partner notification by men who have sex with men.

- Gotz et al. (2014) developed and tested the effectiveness of suggestatest.nl (SAT), an internet-based STI notification system. SAT was piloted in public STI clinics in two major cities in the Netherlands. After counselling a patient for a positive STI test, the nurse logs into SAT and creates a SAT code for the patient. For each sexual partner, the patient can choose to send an anonymous or non-anonymous notification through email, text message, by mail or via a personal message on a dating website. Of 988 individuals who received a positive STI diagnoses, 129 (13%) notified their partner(s) through SAT. Of the partners notified, 58% accessed SAT and 20% subsequently consulted STI clinics. Most notifications were sent anonymously, and SAT notification was only used for 20% of HIV notifications. The greatest implementation challenge was the high numbers of un-contactable partners due to partner anonymity (12).
- Hightow-Weidman et al. (2014) compared Internet Partner Notification (IPN) with text messaging for partner notification (txtPN) and their outcomes in North Carolina. Three hundred and sixty-two contacts were made with IPN, almost exclusively with MSM. Two-thirds of previous partner contacts were successful in notification. Text messages were used for 29 contacts who did not respond to traditional IPN; 48% of these contacts responded (13).

While technological partner notification reminders may not be sufficient on their own, they may be useful in augmenting traditional partner notification services.

### d) Reminders for adherence to antiretroviral therapy

Several reminders for adherence to ART have been found to be effective. The reminders fall into three main categories: text18. Haberer JE, Robbins GK, Ybarra M, Monk A, Ragland K, Weiser SD et al. Realtime electronic adherence monitoring is feasible, comparable to unannounced pill counts, and acceptable. AIDS & Behavior 2012 February;16(2):375-82.

19. Pellowski JA, Kalichman SC. Recent advances (2011-2012) in technology-delivered interventions for people living with HIV. [Review]. Current HIV/AIDS Reports 2012 December;9(4):326-34.

based messaging and smart phone applications, telephone calls, and networked pill box reminders. All of the studies cited below were conducted in the United States, with the exception of the study by Perera, which was conducted in New Zealand.

# i) Text-messaging and smart phone applications

A 2014 meta-analysis by Finitsis et al. (2) assessed eight text-based adherence interventions and found that, overall, the interventions worked. Participants in text-messaging interventions had better adherence than those in the control groups. In examining the various ways in which the interventions had been designed, the authors highlighted the following as important elements:

- text messages should be personalized and tailored to the individual
- text messages should require or elicit a response from the individual
- text messages might be more effective if sent less often than once per day.

The findings by Finitsis et al. (2) are supported by other research.

- Personalized information. In a 2014 New Zealand study that used smart phones to increase adherence, Perera et al. found that an application which incorporated visual imagery providing real-time information about the participant's level of immune function led to significantly higher adherence than a control application which simply showed a 24-hour clock and the participant's dosing schedule (4).
- Requiring a response.
  - In a 2013 study by Hailey et al., youth living with HIV were initially sent a text message reminding them to take their medication. The youth then had to send a message back, however, youth were also able to send texts about refills, shortages, questions and adverse effects. Over the course of 24 months, youth enrolled in

the study showed significant increases in adherence rates (40-50% at baseline to 80% after 24 months) (5).

- In a 2013 study by Lewis et al., adult MSM received "tailored" text messages over three months and answered weekly adherence questions using text messaging (with their answers being fed into the next tailored messages). The authors found that 93% of participants reported "always" reading the messages, and that self-reported adherence improved among participants who had begun the study as non-adherent (6).
- Sending texts daily. In a 2012 study by Dowshen et al., youth living with HIV designed their own personalized text messages that were sent to them daily, as well as follow-up daily texts asking if they had taken their medication and requesting a response. Self-reported adherence scores increased significantly at weeks 12 and 24; however, CD4 cell counts and viral loads remained unchanged during this period (16).
- ii) Cell phone call reminders

Cell phone calls have also proven effective in promoting ART adherence. In a 2014 study by Belzer et al., youth living with HIV received daily cell phone calls from "adherence facilitators" who provided medication reminders and problemsolving support, and referred youth to services that would help them address adherence barriers. During the 24-week intervention, the cell phone group had significantly higher self-adherence than those in the control group. Viral load measurements were lower in the intervention group at both 24 and 48 weeks follow-up (1).

However, a 2013 study by Robbins et al., which assessed the impact of site-nurse initiated adherence and support calls for HIV-positive individuals starting ART, found no significant difference between participants in the intervention arm compared to those in the control arm (who were receiving standard care without additional calls). The authors suggested that, since selfreported adherence was exceptionally high in both groups, the calls had limited ability to demonstrate any additional benefits (17).

iii) Internet-connected pill boxes

A 2012 study by Haberer et al. examined a "second generation" pill box (called the *Med-eMonitor*) to monitor HIV adherence. Unlike a traditional pill box, the *Med-eMonitor* records the date and time that pills are accessed, and can transmit this data in real time back to a medical office. The pill box can also display electronic messages about why a medication needs to be taken, and it can alert someone who is about to take medication off-schedule. Although the study was about the feasibility and acceptability of *Med-eMonitor*, 79% of people living with HIV who participated in the study said that the device made it easy to remember when to take their pills (18).

Limitations of using cell phones for

text message reminders

Although modern technology does open up new reminder possibilities for ART adherence, researchers note that technology also creates a unique set of challenges. In the case of youth, cell phones might be lost or numbers might change (5); confidentiality is also an issue for people who share phones (5). Since text messages are designed to be read (and since they remain on a phone until deleted), two studies (5;16) allowed participants to write coded reminder messages.

In addition, a 2012 review by Pellowski et al. noted that, while text message reminders in particular seem effective, more research on measures other than self-reported adherence and larger trials are still needed to determine statistical power and generalizability of results (19).

### Factors That May Impact Local Applicability

All studies cited in this response were conducted in the United States or in other high income settings. To reflect rapid technological change, studies were limited to those published since 2010.



We searched Medline using HIV (text term OR MESH term) in combination with Reminder Systems or Text Messaging (MESH terms) OR telephone or cellular phone or cell phone or mobile or remind\* or electronic or alarm\* or text\* or prompt\* or online or digital or software or alert\* or computer\* (text terms). The search was conducted on 28 May 2015 and articles were limited to those published since 2010 in English. We only included studies from high-income countries. Reference lists of identified studies were also reviewed.

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