STUDY PROTOCOL

Effectiveness of a personalized health profile on specificity of self-management goals among people living with HIV in Canada: a protocol for a blinded pragmatic randomized controlled trial
[version 1; peer review: awaiting peer review]

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Abstract

Background: Goal setting is a crucial element in self-management of chronic diseases. Personalized outcome feedback is needed for goal setting, a requirement for behavior change. This study contributes to the understanding of the specificity of patient-formulated self-management goals by testing the effectiveness of a personalized health outcome profile.

Objective: To estimate among people living with HIV, to what extent providing feedback on their health outcomes, compared to no feedback, will affect number and specificity of patient-formulated self-management goals.

Methods: A personalized health outcome profile has been produced for individuals enrolled in a Canadian HIV Brain Health Now cohort study at cohort entry and at the last recorded visit. Participants will be randomized to receive or not “My Personal Brain Health Dashboard” prior to a goal setting exercise. Self-defined goals in free text will be collected through an online platform. Intervention and control groups will receive instructions on goal setting and tips to improve brain health. A total of 420 participants are needed to detect a rate ratio (number of specific words/numbers of person-goals, intervention:control) of 1.5. Text mining techniques will be used to quantify goal specificity based on word matches with a goal-setting lexicon.

The expectation is that the intervention group will set more goals and have more words matching the developed lexical than the control group. The total number of words per person-goals will be calculated for each group and Poisson regression will be used to estimate the rate ratio and 95% confidence intervals.
confidence intervals and compare rate ratios between men and women using an interaction term.

**Conclusions:** This study will contribute to growing evidence for the value of person-reported health outcomes in tailoring interventions, and will provide a thorough understanding of the quality of person-defined goals using text mining.

**Trial registration:** Clinical Trials [NCT04175795](https://clinicaltrials.gov/ct2/show/NCT04175795), registered on 25th November 2019.

**Keywords**
Goal specificity, HIV/AIDS, Personalized feedback, Self-defined goals, Text mining

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Abbreviations
ABHN: Action for Brain Health Now; B-CAM: Brief Computerized Cognitive Ability Measure; BHN: Brain Health Now; CCM: Chronic Care Model; HIV: Human Immunodeficiency Virus

Introduction
Better antiretroviral treatment in the last two decades means that HIV infection can now be considered a chronic disease\(^1\). Like any other chronic condition, the optimal management of HIV now involves delivery of needs-based services across the HIV care continuum\(^2\).

As the life expectancy of people with HIV becomes more similar to that of the general population\(^3\), the focus is shifting to the issues adults living with HIV are facing as they age\(^4\), such as a higher risk of developing other chronic diseases\(^5\). It is estimated that by 2030, three in four HIV infected adults will be over the age of 50, an age at which more than 80% will have at least one age-related disease\(^6\). A higher prevalence of age-associated diseases in HIV-infected adults appears to be a consequence of extended exposure to both HIV and antiretroviral treatment that impede successful aging\(^7\).

Multiple chronic conditions can interact to diminish a person’s well-being and quality of life\(^8\). As a result of the contribution of HIV to higher prevalence of chronic conditions, HIV needs to be viewed both as a single chronic disease as well as a precursor to other chronic diseases\(^9\).

There is mounting evidence that shows that management of a chronic disease goes further than just symptom management and involves addressing the biopsychosocial aspects of health in particular self-management and quality of life. The management of chronic conditions has been mainly based on the Chronic Care Model (CCM)\(^10\), a holistic approach that takes into account the role of the health care system, community, and the person. Self-management is the crucial component of the CCM and encompasses developing skills and confidence to take charge of biopsychosocial adjustments that are necessary due to a chronic condition\(^11\). The concept of self-management support is based on delivering meaningful and relevant information to patients and help them set goals and make choices that lead to improved health outcomes over time. This is to help patients become the principal caregivers and decision-makers with respect to their own health condition\(^12\).

Goal setting – a unique aspect of self-management
Goal setting occupies a pivotal place in self-management of chronic conditions. Self-management interventions that include a goal setting component have been shown to be effective in increasing patients’ progress towards better health outcomes in the face of chronic diseases\(^13\). Patient-centered goals are defined as goals set with patients actively engaged, through discussing goals, setting plans, and evaluating their condition afterwards\(^14\).

Until now, studies on goal setting in chronic disease management have used goal setting as a means to improve health outcomes with goals set collaboratively. Self-defined goals, without clinicians’ input, have not received much attention. It could be argued that at the population level, where there is no direct input from the healthcare professionals, setting good quality goals and making plans for action are difficult and can threaten achievement of targeted health outcomes.

One possible strategy to empower patients to self-manage their condition is providing feedback through sharing specific information about their health profile to stimulate the setting of specific goals\(^15\). Previous studies show that personalized feedback is more effective for improvements in lifestyle behaviors, specifically in terms of health risk indicators, such as body mass index, diet, and physical activity\(^16,17\). Personalized rather than general feedback is more accepted by patients for management of health and well-being as they can relate it to their own health targets and make informed choices about risk assessment and lifestyle modification\(^18\). This study contributes to the understanding of the quality of patient-formulated self-management goals (hereafter self-defined goals) by testing the effectiveness of providing feedback using a personalized health profile.

Objectives
This study aims to estimate, among people living with HIV, to what extent providing feedback on their health outcomes, compared to no feedback, will affect number and specificity of self-defined goals.

Conceptual model for the present study
Individuals set their health-related goals according to their personal health reference point – “the level of mental, emotional, and physical health people believe possible or necessary to make the progress they seek”\(^19\). A health reference point is formed by the individuals’ health status and circumstances and the trade-offs they are willing to make. Health feedback profiles can provide an understanding of the health reference point that can enable individuals to set goals that ultimately produce the desired effect on health outcomes. Because deterioration in the health outcomes of people with a chronic condition occur over a long time period, goal setting can be used as an intermediate step to raise awareness of areas for improvement and set in place action plans. These are the building blocks of self-management.

Cognitive ability is one factor that could modify the effect of health feedback on self-defined goals. Cognitive deficits such as problems with memory, attention, comprehension, executive functioning, or speed of information processing are likely to interfere with writing high quality goals\(^20\). As self-management approaches have mostly been implemented as part of clinical programs, the recommendations have been tailored to the individual’s cognitive capacity\(^21\). Figure 1 depicts the relationships explained above.

Methods
This is version 1 of the protocol.

Context for the study: Brain Health Now (BHN)
This project is a sub-study of the BHN study (http://brainhealthnow.mcgill.ca), which is a multi-site Cohort Multiple Randomized Controlled Trial (cmRCT) across five sites in Canada\(^22\).
This design is based on using a fully characterized cohort as the basis for recruiting people into multiple trials. The characterization of the cohort was based on the Wilson-Cleary model, a biopsychosocial model integrating multiple components of health-related quality of life\textsuperscript{14}. The particular focus is brain health, recognized as a multi-dimensional construct reflecting the brain’s role in cognition, mood, emotional stability, motivation and energy\textsuperscript{15}. The outcome measurement strategy for the BHN comprised 20 different self-report, patient-reported outcome measures, one performance outcome measure, as well as questions about age, sex, education, drug and alcohol consumption, smoking, and nutrition. Cognitive ability of all participants has been measured with the Brief Cognitive Ability Measure (B-CAM).

The first phase of the study – Positive Brain Health Now (+BHN) – was conducted over the course of 5 years from 2013 to 2018, recruiting and characterizing more than 800 HIV+ men and women with four assessments, scheduled 9 months apart. Details of this study have been published elsewhere\textsuperscript{30,33,34}. This cohort has been extended (Action for Brain Health – ABHN) to cover the period until 2023 with annual follow-up.

This study has been approved by institutional research ethics (McGill University Health Centre Research Ethics Board, ABHN_Goals 2020-5728) and was registered as a trial on Clinicaltrials.gov NCT04175795.\textsuperscript{31}

Study design
A blinded, stratified, pragmatic randomized controlled trial design will be used to assess the impact of the personalized health feedback profile on the number and specificity of self-defined goals. Participants will be randomized (1:1 allocation ratio) into one of two groups, the intervention or control group, stratified based on gender. The randomization is computer generated by the study statistician using randomization.com. For this study, it will not be possible to blind the participants as the intervention is their personalized health profile. To avoid bias in assessing outcomes, those collecting and analyzing the data will be kept blind to group assignment.

Study population
The study population for this trial, ABHN_Goals, is people who were enrolled in either +BHN study or its extension (ABHN) who agreed to be contacted for further sub-studies and who have access to the internet. Briefly, cohort members were people HIV+ for at least 1 year. Excluded were people with dementia, co-morbidity affecting cognition, substance abuse, or life-threatening illnesses\textsuperscript{35}.

Study procedure
All +BHN participants who consented for sub-studies will be contacted by the intermediary staff (i.e., designated research assistants) either by phone or e-mail to be recruited for this study. Participants will be asked to provide and/or confirm their e-mail addresses so that an e-mail containing the information regarding the study, their unique access code, and the link to access a specialized web-based goal setting platform (available in French and English) could be sent to them. The intervention group will receive their Dashboard via e-mail along with instructions on goal setting and tips to improve brain health. The control group will receive only the goal setting instructions and tips. Figure 2 shows the study flow diagram.

Data collection will be through a web-based goal setting platform (LimeSurvey hosted on a McGill server). All participants will receive a token to access to the platform. After electronically signing the consent form (Extended data\textsuperscript{36}), participants will be directed to the main page to write their goals and fill out questions that follow each goal. Participants in both groups will be asked to think of the top 3 to 5 actions they would like to take to improve their health condition in the assigned boxes. For each goal, participants will be also asked questions about their self-regulatory plans (i.e., barriers and potential solutions).

A maximum of 2 weeks will be considered so that participants can think and reflect on their goals (a reminder e-mail will be sent after the first week). Participants who do not answer the survey within the two weeks will receive a second reminder e-mail to fill out the online survey. Participants who do not answer to the survey after the second reminder will not be re-contacted. At the end of the study (2 weeks + 2 weeks extension after the second reminder e-mail = 4 weeks in total for each participant), participants in the control group will receive their Dashboard via e-mail. Only research assistants will be in communication (phone and/or email) with participant. No in-person visit is required for this project. Step by step instruction as to how fill out the survey has been also made as a PDF file in English and French for participants who might need some help filling out the survey.

Intervention
The intervention tested in this study is inspired by the knowledge-to-action framework\textsuperscript{36}. It involves providing feedback

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**Figure 1. Conceptual model.**

[Image 103x612 to 510x706]
[about modifiable contributors of health and quality of life] by sending participants their personalized health profiles. As part of the knowledge translation plan, a personalized profile of specific actionable health outcomes with evidence of life impact[34,37] termed as “My Personal Brain Health Dashboard” has been created for each BHN participant (Figure 3). The Dashboard has 15 different actionable items (selected from pre-existing validated measures) and covers information on brain health outcomes, health and quality of life ratings, and lifestyle factors. All items have sufficient track record of validity and are known as a reasonable substitute for multi-item questionnaires for obtaining and monitoring patient relevant outcomes “on aspects of health that only patients can report (e.g., stress, pain, fatigue, etc.)”[38]. Cognitive debriefing interviews were conducted with members of the HIV community in Montreal and Vancouver to pre-test the Dashboard for its interpretability and usefulness for goal setting. Interpretability of the Dashboard was improved by minor modifications to item wording, adjustment of colors to differentiate outcome categories, and adding extra explanations.

A requirement for setting achievable goals is that people have contemplated and prepared themselves to set goals and take actions. However, if patients do not realize that there are aspects of their life that are suboptimal and amenable to intervention, they cannot set goals for targeting these areas. Our hypothesis is that the Dashboard helps patients to formulate achievable goals by helping them to understand their health status. The Dashboard is designed to 1) provide a summary of patients’ health outcomes in terms of their cognitive and physical functionality, emotions, perception of health and quality of life along with changes in these health outcomes over time between their visits and 2) help patients compare their results with the optimal range and see how far or close they are to reach the target. This way, patients would be prepared to move towards identification of topics for setting goals. The Dashboard will act as a prepared list of items where patients can find the areas that they need to improve, select, prioritize, and set goals for. As mentioned earlier, cognitive ability of all BHN participants has been measured with the B-CAM. This study is thus ideally placed to take into account the effect of cognitive ability on goal setting.

Figure 2. Flow diagram for goal setting trial in HIV cohort.
Dear participant,

You were enrolled in the "Positive Brain Health Now" study during 2013–2018. The objective of the study was to identify, understand, and optimize brain health in people living with HIV. We asked you to fill out questionnaires and perform some computer tests during your visits at the clinic. By answering the questionnaires, you helped us to understand your physical and psychological status, as well as your perception of your quality of life. Your performance on the computer test enabled us to evaluate your cognitive status. We would like to share these results with you. To this end, based on your answers, we have created a Dashboard for you called "Your Personal Brain Health Profile". All the items you see on this Dashboard are aspects of health that influence your brain health and in general your quality of life.

This Dashboard is easy to read: on the left side you will see all the items. The middle columns are your results on the first and last visit you had during the study. The column on the right provides the optimal values for each item. Your result for each item is color coded based on how far on close your values were compared to the optimal values. You can find the colours codes at the bottom of the Dashboard.

You might find that your status for some of the items on the Dashboard has been changed (to better or worse). This Dashboard is based on how you evaluated yourself at the time of your visit. You can find the date for your first and last visit on the Dashboard. However, you can still use the items and evaluate yourself for today and see whether or not you meet the optimal level.

This Dashboard is designed for all who participated in the "Positive Brain Health Now" study to help them think about their health and identify aspects of life where some actions might be needed. The Dashboard gives you feedback on 15 items. Here are some explanations for how these items were measured:

<table>
<thead>
<tr>
<th>Items on your Dashboard</th>
<th>How they were measured?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Cognitive test score</td>
<td>This was evaluated by a computer test.</td>
</tr>
<tr>
<td>2 Your evaluation of your memory</td>
<td>You filled out a questionnaire and answered questions about your memory status</td>
</tr>
<tr>
<td>3 Able to concentrate</td>
<td>Your were asked to think about the last 2 weeks and answer how well are you able to concentrate?</td>
</tr>
<tr>
<td>4 Negative feelings (blue mood, despair, anxiety, depression)</td>
<td>You were asked to think about the last 2 weeks and answer how often do you have negative feelings such as blue mood, despair, anxiety, depression?</td>
</tr>
<tr>
<td>5 Feeling lonely</td>
<td>You were asked whether or not you find yourself feeling lonely?</td>
</tr>
<tr>
<td>6 Time feeling worn out</td>
<td>You were asked to think about the last 4 weeks and answer how much of the time did you feel worn out?</td>
</tr>
<tr>
<td>7 Feeling rested after waking up</td>
<td>You filled out a questionnaire with focus on your sleep status</td>
</tr>
<tr>
<td>8 Your pain rating</td>
<td>You were asked to think about the last 4 weeks and answer how much bodily pain did you have?</td>
</tr>
<tr>
<td>9 Climbing several stairs</td>
<td>You were asked how much you find yourself limited in climbing several stairs?</td>
</tr>
<tr>
<td>10 Walking more than a kilometer</td>
<td>You were asked how much you find yourself limited in walking more than a kilometer?</td>
</tr>
<tr>
<td>11 Vigorous activities</td>
<td>You were asked how much you find yourself limited in doing vigorous activities?</td>
</tr>
<tr>
<td>12 Weight to height ratio (BMI)</td>
<td>We measured your weight and your height, and this value shows whether your weight in proportion in your height is healthy or nor.</td>
</tr>
<tr>
<td>13 Smoking</td>
<td>You were asked if you are a current smoker?</td>
</tr>
<tr>
<td>14 Health rating</td>
<td>You were asked, in general how would you say your health is?</td>
</tr>
<tr>
<td>15 Quality of life</td>
<td>You were asked how you would rate your quality of life?</td>
</tr>
</tbody>
</table>
Figure 3. My Personal Brain Health Profile.

<table>
<thead>
<tr>
<th>Important Brain Health Areas</th>
<th>Your first visit</th>
<th>Your most recent visit</th>
<th>Optimal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visit date</td>
<td>October 29, 2013</td>
<td>January 13, 2016</td>
<td></td>
</tr>
<tr>
<td>Cognitive test score</td>
<td>Excellent</td>
<td>Good</td>
<td>Excellent</td>
</tr>
<tr>
<td>Your evaluation of your memory</td>
<td>Good</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Able to concentrate</td>
<td>A moderate amount</td>
<td>A moderate amount</td>
<td>Very much to</td>
</tr>
<tr>
<td>Negative feelings (blue mood, despair, anxiety, depression)</td>
<td>Quite often</td>
<td>Seldom</td>
<td>Never or</td>
</tr>
<tr>
<td>Feeling lonely</td>
<td>Sometimes</td>
<td>Sometimes</td>
<td>Almost never</td>
</tr>
<tr>
<td>Time feeling worn out</td>
<td>A little</td>
<td>Some</td>
<td>None to a little</td>
</tr>
<tr>
<td>Feeling rested after waking</td>
<td>Never</td>
<td>Never</td>
<td>Often or always</td>
</tr>
<tr>
<td>Your pain rating</td>
<td>None</td>
<td>None</td>
<td>None to mild</td>
</tr>
<tr>
<td>Climbing several stairs</td>
<td>Limited a little</td>
<td>Not limited</td>
<td>Not limited</td>
</tr>
<tr>
<td>Walking more than a kilometer</td>
<td>Limited a little</td>
<td>Limited a little</td>
<td>Not limited</td>
</tr>
<tr>
<td>Vigorous activities</td>
<td>Limited a little</td>
<td>Limited a little</td>
<td>Not limited</td>
</tr>
<tr>
<td>Weight to height ratio (BMI)</td>
<td>27</td>
<td>25</td>
<td>Between 19 and 25</td>
</tr>
<tr>
<td>Smoking</td>
<td>Smoking</td>
<td>Smoking</td>
<td>Not smoking</td>
</tr>
<tr>
<td>Health rating</td>
<td>Very good</td>
<td>Very good</td>
<td>Excellent, very good</td>
</tr>
<tr>
<td>Quality of life</td>
<td>Good</td>
<td>Good</td>
<td>Good, very good</td>
</tr>
</tbody>
</table>

The green boxes indicate areas where you are in the optimal state.
The neutral boxed indicate areas where you are below the optimal state but not too far away.
The orange boxes indicate areas where you are further away from the optimal state.
Number of optimal areas at my first visit = 5
Number of optimal areas at my most recent visit = 6

Main outcome
This study will test the hypothesis that providing feedback to people living with a chronic condition such as HIV, using personalized health profile, results in a person’s higher ability to formulate specific goals. The two main outcomes in this study are the number and specificity of self-management goals. For goal specificity, text mining techniques will be used. This outcome will be reported as a discrete variable – number of specific words (matched to a developed lexicon) per person-goals. The expectation is that the intervention group will set more goals and have more words matching the lexicon than the control group. The numerator for this estimator is total number of specific words per group; the denominator is the number of cumulated number of goals set per person (e.g., if 10 people set 5 goals each, this represents 50 person-goals).

Patient goals are mostly formulated collaboratively with the client and a clinician according to SMART criteria, which facilitates setting good quality goals. There are no standardized and validated measuring criteria for goal formulation. Furthermore, the literature on goal setting shows that goals are most often evaluated according to the person’s progress towards their goal or the outcome (i.e., measure of change)19.

To measure the quality of self-defined goals, which most often lack the structure and format of clinically SMART goals, techniques of text mining would appear to be well suited. Text mining helps us to extract and understand specific elements of the goals from the textual data. In this study, text mining techniques and algorithms will be used to 1) distinguish components of a patient goal, 2) evaluate specificity of components in a person goal according to our previously collected vocabularies (lexicon), and 3) expand our lexicon based on mass evaluation of around 400 to maximum 2000 self-defined goals.

Overview of the text mining procedure
We have created an initial lexicon (i.e., start list of words; Extended data”). Our lexicon contains two separated lists of vocabularies. One list contains words that convey vague information and another list contains words that make goals more specific. This lexicon was made using two sources of data. The first was a set of goals set collaboratively (with a healthcare professional) during a project on health outcomes post-hospitalization. Words that represented each component of SMART criteria were manually extracted. The second source arose from cognitive interviews conducted with members of HIV community piloting a goal setting exercise for this future trial. Those words that corresponded to each component of SMART criteria were also manually extracted. This preliminary list of words was presented to a multidisciplinary group of

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1SMART - A widely used criteria to guide setting goals which stands for specific, measurable, action-planned, realistic, and time-bound goals.
researchers and clinicians familiar with goal setting in the field of physiotherapy, occupational therapy, psychology, epidemiology, and nursing. Through this process, initial goal setting lexicon was shaped.

Next, lemmatization function will be used to reach the root (i.e., word’s lemma) of the words in the lexicon. This process, lemmatization, will be done in order to enrich the lexicon with words that have similar meanings to the words in our lexicon, synonyms. A set of guidelines has been defined for evaluating each component of the goals. The guideline and further details of the text mining algorithms are explained in the Extended data.

Self-defined goals (written in English or French) in text format will be classified using text mining algorithms to find words that represent components of SMART (available in the lexicon). Total number of words per person-goals that match the lexicon will be reported according to the components of SMART.

Analytical approach
The main outcome of this study is a rate, based on the cumulated count of the number of specific words per person-goal. Thus, the analysis aims to compare rates of the response variable (i.e., word count/person-goal) across groups. The total number of specific words per person-goals will be calculated for each group and Poisson regression will be used to estimate the rate ratio and 95% confidence intervals and compare rate ratios between men and women using an interaction term:

\[
\log(\text{E(Rate of Goal Specificity)}) = (\text{groups}) + (\text{Gender}) + (B-CAM scores) + (\text{groups} \times B-CAM scores)
\]

Characteristics of participants (e.g., age, sex, education, employment status, etc.) in both groups will be analyzed using descriptive statistics. SAS 9.4 software (SAS Institute Inc) will be used for statistical analysis.

Confidentiality
All personal and demographic information of participants have been collected during the BHN study. All direct identifiers such as names and email addresses have been removed and is only available to the research assistants who are responsible for recruitment. Participants are all identified by a code number (username assigned to them). All information that is collected for the study will be kept in a secure and password protected file and stored for 7 years at the Centre for Outcome Research and Evaluation, McGill University Health Centre research Institute.

Sample size
The sample size calculation for this “two-arm randomized controlled trial” is based on the requirements for the hypothesis tests for a rate ratio of formulating specific goals with a two-sided level of significance of 5% and a power of 80%. In order to find the value for the null hypothesis, a pilot study with 20 people (10 per group) has been done. Samples of goals have been collected to compare the difference in the number of specific words per person-goals (i.e., rates) between self-defined goals (i.e., e10) and collaboratively set goals (i.e., e10). For self-defined group, the average number of goals was 3 (30 person-goals) with the mean number of specific words per goal of 4, for a rate of 120/30 or 4. For collaboratively set goals, the average number of goals was 5 (50 person-goals) with the mean number of specific words per goal of 6 for a rate of 300/50 or 6. Using these data, a rate ratio (RR) of 1.5 (6:4) and 95% confidence interval of (1.12, 1.99) was calculated.

Considering equal group allocation, an event rate ratio of 1.5 has been used as the point estimate. Considering a projected survey response of 20%, an estimation of confidence interval for comparison of two proportion showed that a minimum sample size of 210 per group would provide a 95% confidence interval that excludes 1 (i.e., 1.23, 1.83).

Limitations and potential solutions
This study will be the first trial using text mining in the context of goal setting and is not exempt from limitations. A main limitation for this study is the potential for low participation (i.e., low survey response), particularly for the control group as they might be less motivated because they will not be receiving their Dashboards until after survey submission. The measurement and analytic approach of this study requires a relatively high participation rate. Although this has been factored into the sample size calculation, to maximize recruitment, the recruitment and reminder e-mails will remind participants in the control group that their Dashboard will be sent to them shortly after filling out the survey.

Another pitfall facing this study is the potential of ambiguous results. This limitation arises from the complexity of natural language (i.e., words that can have more than one meaning and could be interpreted in different ways according to the context). Several steps will be taken to minimize this problem. First, the preliminary version of the lexicon has been developed using both well formulated goals or supervised goals (i.e., set in collaboration with a clinician following SMART criteria) and self-defined goals (i.e., with a written goal setting instruction). Second, the domain knowledge (i.e., words related to chronic disease and HIV self-management) has been integrated into our lexicon using relevant literature. So far, no text mining tool has included the domain knowledge. Third, different tagging algorithm will be tried to find the most accurate and robust result. Moreover, 20% of the goals will be randomly selected to be evaluated by a panel of 5 experts in the field of rehabilitation goal setting and these results will be compared with the ones obtained through text-mining.

Dissemination
The results of this trial will be publicly available and published in peer reviewed journals and disseminated at relevant conferences and meetings at the completion of the study. This study is novel.

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1Permission to access the data was granted by contacting the primary investigator
in testing the usability of text mining to measure goal quality. The findings of this work will be rigorous and could be used as an example with other chronic health conditions. We aim to share the text mining methodology used in this research and its advantages and limitations in measuring goal quality. Also, we offer a comprehensive goal-related lexicon specific to people living with HIV in Canada. While our sample here is people with HIV, the lexicon could be used as a start point in similar research with other chronic conditions in Canada.

Study status
The start date of the project was January 13, 2020. Recruitment is ongoing; however, due to the COVID-19 pandemic and closure of some outpatient clinics, recruitment has been temporarily shut down.

Discussion
This study will estimate the effectiveness of providing feedback through a personalized health profile as a strategy to improve self-management goals in the target population of people living with chronic diseases. This study will be conducted among people living with HIV. Due to access to antiretroviral treatment, HIV infection has shifted from a disease with a dire prognosis to a manageable chronic condition. Yet, most HIV research is focused on patients’ treatment adherence. Self-management, including goal setting, has received little attention. To our knowledge this will be the first intervention study on goal setting in an HIV+ population in Canada or elsewhere.

Developing SMART goals is usually done one-on-one with the collaboration of a healthcare professional. However, this approach is not feasible for the general population. In this study, the implementation of goal setting will be expanded by using a Dashboard as a method to stimulate individuals’ insight on their health condition. This Dashboard is unique in that it goes beyond physical health and involves aspects of the person as a whole, informed by health and quality of life ratings and lifestyle factors. All the items on the profile are modifiable contributors of health and quality of life. Presenting an optimal range in the profile allows participants to compare their status with the target range and plan their goals accordingly. The results of this study will also contribute to the clinical practice by informing clinicians about the specific health concerns of people living with a chronic condition — particularly HIV — that can be targeted for follow-up support.

Moreover, this study will add to our understanding of the quality of patient-formulated goals. We are taking a novel approach to evaluate the quality of person-formulated goals using text mining. Text mining allows extracting specific information from participants’ goals. The process of text mining allows to 1) build a comprehensive goal-related lexicon specific to people living with HIV in Canada, 2) explore participants’ most common health-related goals through identifications of clusters, and 3) provide evidence necessary for future studies using text mining as an inexpensive and timely way for evaluation of textual information.

Data availability
Underlying data
No underlying data is associated with this article.

Extended data
Open Science Framework: Goal Setting in HIV, https://doi.org/10.17605/OSF.IO/FW4SX.

This project contains the following extended data:
- Goal evaluation guideline for text mining
- Text mining steps
- Informed consent form for participants
- Initial start-up lexicon (English and French)

Reporting guidelines

Data are available under the terms of the Creative Commons Zero “No rights reserved” data waiver (CC0 1.0 Public domain dedication).

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References


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