Effectiveness of a personalized health profile on specificity of self-management goals among people living with HIV in Canada

Maryam Mozafarinia, B.Sc. (Nursing), M.Sc. (Nursing)

Division of Experimental Medicine

Faculty of Medicine and Health Sciences

McGill University

Montreal, Quebec, Canada

April, 2021

A thesis submitted to the Faculty of Graduate Studies and Research

in partial fulfilment of the requirement of the degree of

Doctor of Philosophy (Experimental Medicine)

In dedication to

mom **Sorayya Afsharmehr** *& dad* **Saeed Mozafarinia**

As a small token of appreciation and affection

TABLE OF CONTENTS

Index for Tables

Supp.: Supplementary

Index for Figures

Abstract

Chronic conditions remain the greatest global health challenge. Some previously known terminal conditions, such as HIV, have transformed into chronic conditions. The global aging population is growing and thus the age-related diseases and the exponential increase of morbidities. These trends have intensified the struggle of healthcare systems to cope with the demands of the chronic conditions. The burden of chronic conditions has led to the proliferation of many self-management interventions to help patients manage diverse effects of their chronic conditions. Goal setting is one main pillar of self-management. While it has been largely incorporated within self-management interventions as a means to improve health outcomes, little has been reported on goal formulation and the extent of goal exchange between patients and caregivers.

People set goals based on their health reference point – shaped by their underlying clinical condition and perception of their capability for self-managements. Yet not everyone is aware of their reference points nor is informed of their status on health aspects of quality of life according to health practice standards. Thereby, the questions raised are whether people living with chronic conditions, particularly those with multifaceted problems such as HIV, are ready to set their own self-management goals and whether a health profile could facilitate goal formulation? Taking HIV as an example of a chronic condition, the aim of this thesis is to contribute evidence towards self-management capability of people living chronic conditions.

To achieve this overall goal, this thesis entailed five distinct components.

Manuscript 1, entitled "*An umbrella review of the literature on the effectiveness of goal setting interventions in improving health outcomes in chronic conditions*", provided a comprehensive review of goal setting interventions in the context of chronic disease management. In this work, a total of 7 systematic reviews with 125 primary studies were reviewed to identify the components

of goal setting interventions and to estimate the magnitude of goal setting effect on improvement of health outcomes. The evidence was suggestive of little or no likelihood of achieving the intended health outcomes based on the solo effect of goal setting, even though some degrees of change was shown. This umbrella review highlighted that episodic health outcomes or short follow-ups cannot represent the effect of goal setting. In addition, insufficient details of goal setting interventions did not allow disentangling the extent of patients' involvement in the process. Findings of this umbrella review further triggered the question as to whether patients are prepared for setting self-management goals for their real-world condition.

Manuscript 2 entitled "*Development and usability of a feedback tool, "My Personal Brain Health Dashboard", to improve setting of self-management goals among people living with HIV in Canada*" was inspired by the knowledge-to-action framework and used longitudinal data acquired from a Canadian longitudinal study on multiple domains of quality of life. The aim of the feedback tool (termed Dashboard) was to improve people's understanding of their health reference point by providing meaningful information on their adjustment with chronic condition. Through this work fifteen HIV+ respondents were recruited from Montreal and Vancouver and appropriateness of the Dashboard for goal-setting was tested. The Dashboard was endorsed as a useful tool for setting health-related goals. A total of 85 goals were set, which served as a textual data for expansion of a goal setting lexicon for scoring goal quality presented in subsequent manuscripts.

The content and layout of the Dashboard was intended to help improve individuals' ability to reflect on their own health status, make choices, and set self-management goals that would eventually lead to improved health outcomes. **Manuscript 3** documented the protocol for a pragmatic trial designed to test this hypothesis.

Manuscript 4 entitled "*Effectiveness of a personalized health profile on specificity of self-management goals among people living with HIV in Canada: findings from a blinded pragmatic randomized controlled trial*" was to estimate whether providing feedback on health outcomes, compared to no feedback, will affect number and specificity of self-defined goals. This study was a subset of a cohort multiple randomized controlled trial which provided access to the participants who were eligible. A total of 110 survey responses (56 in English/54 in French), entailing 421 goals, were analyzed. Findings suggested of no positive effect of the Dashboard on the primary outcomes. Similar performance and goal quality were observed in both groups. This work involved a novel approach towards measuring goal quality where text mining algorithms detected predefined goal criteria. Level of agreement between individual raters and text mining output confirmed text mining's potential to remove hurdles in goal evaluation outside of the face-to-face setting.

Lastly, a qualitative secondary analysis was caried out to tackle influences of self-management goals judged by the persons living the condition. Findings of **Manuscript 5** entitled "*Barriers and enablers to acting on self-management goals among people living with HIV in Canada*" informed that HIV+ people are able to report their priorities, areas of challenges, and potential facilitators.

Self-management is a powerful idea, provided that it is successfully translated from an idea to the daily reality of people concerned where people's priorities and capacity to change are considered. Self-management at population-base is time and resource intensive. The growing domain of digital health offers opportunities that could be used to help improve self-management skills of people living with chronic conditions. The novel approach towards measuring goal quality presented in this thesis illustrates one example of such opportunity.

Résumé

Les maladies chroniques demeurent le plus grand défi du domaine de la santé autour du monde Certaines maladies autrefois connues comme fatale, par exemple le VIH, se sont transformées en maladies chroniques. La population vieillissante augmente mondialement, tout comme les maladies liées à l'âge et l'augmentation exponentielle des morbidités. Ces tendances ont intensifié la lutte des systèmes de santé pour faire face aux exigences des maladies chroniques. La charge des maladies chroniques a mené à la prolifération de nombreuses interventions d'autogestion pour aider les patients à gérer les divers effets de leurs maladies chroniques. La fixation d'objectifs est l'un des principaux piliers de l'autogestion. Bien qu'elle ait été largement intégrée dans les interventions d'autogestion comme un moyen d'améliorer les résultats de santé, très peu d'études ont été réalisées sur la formulation des objectifs et l'étendue de l'échange d'objectifs entre les patients et les soignants.

Les gens se fixent des objectifs en fonction de leur point de référence de santé - déterminé par leur état clinique sous-jacent et la perception de leur capacité d'autogestion. Cependant, tous ne connaissent pas leur point de référence de santé et ne sont pas informés de leur état concernant les aspects de la qualité de vie liés à la santé, comparé aux standards. Par conséquent, les questions soulevées sont les suivantes : les personnes vivant avec des maladies chroniques, en particulier celles qui ont des problèmes à multiples facettes comme le VIH, sont-elles prêtes à fixer leurs propres objectifs d'autogestion ? et un profil de santé pourrait-il faciliter la formulation des objectifs ? En prenant le VIH comme exemple d'une maladie chronique, l'objectif de cette thèse est de contribuer aux évidences scientifiques sur la capacité d'autogestion des personnes vivant avec une maladie chronique.

Pour atteindre cet objectif global, cette thèse comprend cinq éléments distincts.

Le Manuscrit 1, intitulé " *Une revue générale de la littérature sur l'efficacité des interventions de fixation d'objectifs dans l'amélioration des résultats en matière de santé dans les maladies chroniques* ", a fourni une revue complète des interventions de fixation d'objectifs dans le contexte de la gestion des maladies chroniques. Dans ce travail, un total de 7 revues systématiques comprenant 125 études primaires a été examiné afin d'identifier les composantes des interventions de fixation d'objectifs et d'estimer l'ampleur de l'effet de la fixation d'objectifs sur l'amélioration des résultats de santé. Les preuves suggèrent qu'il est peu ou pas probable d'atteindre les résultats de santé désirés en se basant sur l'effet de la fixation d'objectifs seulement, même si certains degrés de changement ont été démontrés. Cette revue générale a mis en évidence que les résultats épisodiques en matière de santé ou les suivis de courte durée ne peuvent pas représenter l'effet de la fixation d'objectifs. En outre, le manque de détails sur les interventions de fixation d'objectifs n'a pas permis l'appréciation du degré d'implication des patients dans le processus. Les résultats de cette revue générale ont soulevé la question de savoir si les patients sont préparés à fixer des objectifs d'autogestion pour leur condition réelle.

Le Manuscrit 2 intitulé " *Développement et facilité d'utilisation d'un outil de rétroaction, "Mon Profil Personnel de Santé du Cerveau", pour améliorer la fixation d'objectifs d'autogestion chez les personnes vivant avec le VIH au Canada* " s'est inspiré du cadre de la connaissance à l'action et a utilisé des données acquises dans le cadre d'une étude longitudinale canadienne sur plusieurs domaines de la qualité de vie. L'objectif de l'outil de rétroaction (appelé Profil) était d'améliorer la compréhension des personnes par rapport à leur point de référence en matière de santé en leur fournissant des informations significatives sur leur adaptation à leur condition chronique. Dans le cadre de ce travail, quinze personnes séropositives ont été recrutées à Montréal et à Vancouver et la pertinence du Profil pour la fixation d'objectifs a été testée. Le Profil a été approuvé comme un

outil utile pour fixer des objectifs de santé. Au total, 85 objectifs ont été fixés, qui ont servi de données textuelles pour l'expansion d'un lexique de fixation d'objectifs permettant d'évaluer la qualité des objectifs présentés dans des manuscrits ultérieurs.

Le contenu et la présentation du Profil devaient contribuer à améliorer la capacité des individus à réfléchir à leur propre état de santé, à faire des choix et à fixer des objectifs d'autogestion qui conduiraient à terme à une amélioration des résultats de santé. **Le Manuscrit 3** documente le protocole d'un essai pragmatique conçu pour vérifier cette hypothèse.

Le Manuscrit 4, intitulé " *Efficacité d'un profil de santé personnalisé sur la spécificité des objectifs d'autogestion chez les personnes vivant avec le VIH au Canada : résultats d'un essai contrôlé randomisé pragmatique en aveugle* " visait à évaluer si le fait de fournir une évaluation sur l'état de santé, comparativement à l'absence de l'évaluation, aura une influence sur le nombre et la spécificité des objectifs définis par le participant. Cette étude était un sous-étude d'un plus gros essai contrôlé randomisé à cohortes multiples, qui a donné accès aux participants admissibles. Un total de 110 réponses à l'enquête (56 en anglais/54 en français), impliquant 421 objectifs, ont été analysé. Les résultats suggèrent qu'il n'y a pas d'effet positif du Profil sur le résultat principal. Des performances et une qualité d'objectifs similaires ont été observées dans les deux groupes. Ce travail a impliqué une nouvelle approche de la mesure de la qualité des objectifs, pour laquelle des algorithmes d'exploration de texte ont détecté des critères d'objectifs prédéfinis. Le niveau d'accord entre les évaluateurs individuels et les résultats de l'exploration de texte a confirmé le potentiel de l'exploration de texte pour éliminer les obstacles à l'évaluation des objectifs en dehors du cadre du face-à-face.

Enfin, une analyse secondaire qualitative a été réalisée pour aborder les influences des objectifs d'autogestion jugés par les personnes vivant avec la maladie. Les résultats du **Manuscrit 5**

intitulé " *Obstacles et facteurs favorables à l'atteinte des objectifs d'autogestion chez les personnes vivant avec le VIH au Canada* " indiquent que les personnes séropositives sont en mesure de faire état de leurs priorités, de leurs difficultés et de leurs facilitateurs potentiels.

L'autogestion est un outil prometteur, à condition, qu'elle soit traduite avec succès d'une idée à la réalité quotidienne des personnes concernées et que les priorités et la capacité de changement des personnes sont considérées. L'autogestion au niveau de la population mondiale demande beaucoup de temps et de ressources. Le secteur en plein développement de la santé numérique offre des possibilités qui pourraient être utilisées pour aider à améliorer les compétences d'autogestion des personnes vivant avec des maladies chroniques. La nouvelle approche de la mesure de la qualité des objectifs présentée dans cette thèse est un exemple de cette opportunité.

ACKNOWLEDGEMENTS

This section of my dissertation is very special to me as it is about the realities that up until now that I am typing this acknowledgment were only known to me.

I have to start by expressing my profound sense of gratefulness to Professor Mark Goldberg. He was the backbone for supporting my academic enhancement to this level. He introduced me to Professor Nancy E. Mayo and revived my PhD dream – Dr. G. I am forever indebted to you! No words of thanks can sum up the gratitude that I owe my supervisor, Professor Nancy E. Mayo, who graciously offered her skillful guidance, innovative ideas, and stoic patience. She instilled in me the importance of formulating a great research question – Thank you, Dr. Mayo, for going above and beyond the call of duty; for being a leader and making an environment that stimulates original thinking, initiative and collaboration.

I would like to express my sincere appreciation to the Division of Experimental Medicine, especially Professor Anne-Marie Lauzon, Director of the Graduate Program, for giving me an opportunity to fulfill my academic dream. To my committee, Drs. Marie Josée Brouillette, Lesley Fellows, and Bärbel Knäuper and Dr. George Thanassoulis, my academic advisor. Thank you for being the best research committee one could have ever asked. I am extremely grateful for your critical insight and instructive feedback. Thank you for always being welcoming, supportive, accessible and flexible with meetings. To Dr. Fatemeh Rajabiyazdi for her extensive support through the text mining process – thank you for literally holding my hand through each and every step of the work.

To the Positive Brain Health Now team, and all the staff in Montreal, Vancouver, and Toronto who supported me in this project. Special thanks to Amanda Austin Keiller, who was incredibly

PREFACE

Statement of Originality

This thesis constitutes original work which addressed several small gaps within saturated area of chronic disease self-management. The novel contributions of the thesis include: (i) synthesis of evidence on the independent effect of goal setting on health outcomes in a form of an umbrella review for the purpose of making implementation recommendations, (ii) Development and utility testing of a personalized health outcome feedback profile (Dashboard) for people living with HIV; (iii) evaluating the effectiveness of the Dashboard on goal specificity along with application of text mining techniques as a novel method for measuring goal quality; (iv) reporting on HIV+ individuals' capacity to change health-related behaviours based on self-defined goal priorities and perceived barriers, and enablers.

Development of the Dashboard was based on data acquired from a Canadian longitudinal study of brain health in people with HIV. The Dashboard was designed to provide a summary of patients' health outcomes over time as well as a point of reference for self-assessment. This work was unique as dissemination of individual research results to participants is not a common practice and remains as an unmet need of participants. Goal specificity was measured by using text mining algorithms. For this purpose, a goal setting lexicon was developed based on the field knowledge and data from previous goal setting projects. With text mining, textual data representing specific goal criteria was quantified. This was a novel approach towards measuring goal quality given there is no standardized and validated measuring criteria for goal formulation. The output of text mining in this thesis was an enriched goal setting lexicon comprise of about 1000 words of two main parts of speech – noun and verbs – classified as per goal criteria which is unique in its kind. Collection of self-defined goals of people living with HIV allowed hearing

what HIV+ individuals really need and capturing words they use in expressing their need – contributing evidence towards understanding and tackling low health-related quality of life of this population.

Contribution of Authors

This thesis was a part of the Canadian longitudinal cohort study titled "Understanding and Optimizing Brain Health in HIV Now" (BHN cohort, PI: Marie-Josée Brouillette, Lesley Fellows and Nancy Mayo). Participants in this study were members of the BHN cohort.

This thesis was conducted under direct supervision of Dr. Nancy Mayo who oversaw all aspects of the work and provided expert feedback on research methodology and statistical analyses. The manuscripts included in this dissertation are the work of Maryam Mozafarinia with extensive editing and feedback from Dr. Nancy Mayo. For the first manuscript – umbrella review, Dr. Mate was a co-author as he assisted in screening and extraction of data from the systematic reviews. Dr. Rajabiyazdi is a co-author on manuscripts II, III, and IV for her expertise in text mining and for providing editorial feedback on the relevant sections. Text mining procedure conducted in this thesis was under direct and thorough supervision of Dr. Rajabiyazdi. For all the included manuscripts, data analysis, interpretation, and write-up were performed by the doctoral candidate. Dr. Brouillette and Dr. Fellows are co-authors on all manuscripts so as Dr. Knauper (except for one – manuscript II) for their professional insight and critical feedback on the subject area addressed in these manuscripts as well as their editorial feedback.

Thesis Organization and Overview

The thesis comprises five manuscripts in total, two of which have already been published in peer-reviewed scientific journals. In keeping with Graduate and Postdoctoral Studies (GPS)

regulations, an introduction and conclusion independent of the five manuscripts has been incorporated in the thesis. As such, it is important to specify that repetition exists in this context and is inevitable. A brief outline of the thesis is as follows.

Chapter 1 covers an overview on status of chronic conditions around the globe and in Canada with the main focus on chronic HIV. This chapter continues with sections on prevention and control of chronic conditions and introduces the concept of self-management and goal setting.

Chapter 2 covers the rationale behind the thesis and lists the specific objectives addressed in the manuscripts.

Chapter 3 is the first manuscript titled, "*An umbrella review of the literature on the effectiveness of goal setting interventions in improving health outcomes in chronic conditions*". The main objective of this study was to estimate the magnitude of effect caused by goal setting on improvement of health outcomes and to identify the components of goal setting interventions used in the context of chronic disease management. This manuscript is in preparation for submission to the *American Journal of Public Health*.

Chapter 4 links the first manuscript with the second manuscript.

Chapter 5 is the second manuscript titled "*Development and usability of a feedback tool, "My Personal Brain Health Dashboard", to improve setting of self-management goals among people living with HIV in Canada*". This work illustrated the development of a personalized health outcome profile for participants who were enrolled in a Canadian longitudinal study on HIV – Positive Brain Health Now (+BHN). This personalized health outcome profile termed as Dashboard was composed of fifteen actionable items which covered information on brain health outcomes and lifestyle factors. Interpretability of the Dashboard and its utility for goal setting

was tested with a sample of HIV+ individuals. This manuscript was published in the *Quality of Life Research Journal*.

Chapter 6 links the second and third manuscript.

Chapter 7 covers the third manuscript titled *"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"* which provided the methodological and analysis plan for the mentioned trial. This manuscript was published in the *MNI Open Research Journal*.

Chapter 8 links the third and fourth manuscript.

Chapter 9 is the fourth manuscript titled *"Effectiveness of a personalized health profile on specificity of self-management goals among people living with HIV in Canada: a blinded pragmatic randomized controlled trial"*. This study estimated the effect of feedback on health outcomes on number and specificity of self-defined goals taking a text mining approach. The intervention did not yield a positive benefit on the primary outcomes although benefits of text mining approach was observed on measuring goal quality. This manuscript is in preparation for submission to the *Journal of Health Psychology*.

Chapter 10 links the fourth and fifth manuscript.

Chapter 11 is the fifth manuscript titled "*Barriers and enablers to acting on self-management goals among people living with HIV in Canada*". This study explored barriers and enablers of self-management goals using a deductive theory-based approach. Findings provided a deep insight on "what" participants thought they need as means to "act" on their set goals and "how" they perceived they could make it happen. This work informed of key problems people living with HIV are grappling with which affect their health-related quality of life. This manuscript is in preparation for submission to the *Journal of AIDS and Behaviour*.

Chapter 12 is an overall discussion and conclusion based on the previous chapters included in this thesis.

Corresponding figures, tables, and references are presented at the end of each chapter. The references for the published manuscripts have been adapted to fulfil the journal requirements. The references for the other chapters have been provided at the end. Additional information that was not covered in the manuscripts are presented in appendices.

CHAPTER 1: Background

The term 'chronic' is defined as something that is "continuing or occurring again and again for a long time".[1] Chronic diseases are defined as conditions that tend to be of long duration and slow progression even though number of diseases that are covered under this umbrella term varies among professional communities. The top seven worldwide chronic conditions are cardiovascular disease, stroke, cancer, diabetes, obesity, and arthritis.[2] For the better part of the last four decades with the growing crisis of complex chronic conditions, health organizations have advocated for a more sustainable management models by taking a public health approach.[3] A main focus area of this approach is on enabling and empowering patients to become more proactive in managing their health condition.

1.1 Prevalence & Health Outcomes of Chronic Diseases

Chronic conditions are the principal cause of disability and large proportion of premature death.[2] Around one third of world population aged 15 years and above are living with multiple chronic condition.[4] This equals to one in three of all adults which is also the situation for Canadians.[5] According to the Public Health Agency of Canada not only the incidence rate of chronic conditions is increasing every year, but this growth is faster among working age adults.[6] On the other hand, Multiple chronic conditions are far more frequent among older persons which is the situation for nearly 60% of older adults aged 65 and above across the globe.[7,8] These estimates are expected to increase as the population grow older and risk factors continues to mount.[4] Chronic conditions are complex and are driven by various forces including genetic, environmental and behavioural factors[9] and can interact to greatly diminish a person's well-being and quality of life.[6]

The substantial burden of chronic conditions on the healthcare system, individuals concerned, and their families due to the physical, emotional, mental, and financial consequences has been widely reported.[10-12] In Canada, aside from the direct and indirect costs of the chronic diseases, it is estimated that almost 50% of health services are allocated to people who have multiple chronic disease.[13,14] Greater health services demand, work absenteeism or even loss of job, and disability are of major factors escalating economic costs.[6]

The result of the Canadian Chronic Disease Surveillance System (CCDSS) 2016 survey showed that the major chronic conditions that Canadian adults are dealing with fall under five main domains of cancer, diabetes, cardiovascular diseases, chronic respiratory diseases, and mood and anxiety disorders. The latter being more common among the working-age group of 20 to 64 years old.[6] Within the last two decades, acknowledging disease transformation from fatal to chronic,[15] HIV infection has also been added to the list of chronic conditions by many professional communities including Health Canada.[16-18] Today, at the international level and mainly in the Western world, HIV management is no longer dependent on acute services and has shifted from illness management to delivering need-based services across the HIV continuum for its optimal management.[15]

1.2 HIV – A Chronic Manageable Condition

HIV infection is caused by the human immunodeficiency virus. Overtime (with no treatment) the virus causes acquired immunodeficiency syndrome (AIDS) – progressive failure of immune system.[19] With medical breakthroughs, changes in the course of a disease from terminal or acute to chronic is not unexpected.[10] HIV infection is an example of such transition. Scientific advances and access to combination antiretroviral therapy (cART) have changed the trajectory of HIV from a progressive fatal infection to a chronic manageable condition.[20] Although cART is

2

not a cure for HIV, it help suppressing the viral load and preventing disease progression to AIDS.[19]

Approximately 38 million HIV+ individuals are living around the globe.[21] In Canada the prevalence is 5.8 per 10,000 population.[22] Today, life expectancy of HIV+ individuals is almost the same as the general population as long as they stay on medication.[21,23,24] Nonetheless, along with advancements in HIV treatment, come more concerns about the unique issues adults living with HIV are facing as they age.[25]

Due to cumulative exposure to the antiretroviral treatment (ART), people with HIV not only tend to age physiologically a bit earlier than their same-age counterparts (known as accelerated or premature aging), but they are also at higher risk of developing other chronic diseases, such as cardiovascular diseases and diabetes.[15] In fact, it is estimated that by 2030 three in every four HIV infected adults will be over the age of 50 – an age that comes with an increased risk of age-related disease.[26] A changing and aging HIV population advises that much of the gained life expectancy will be spent with wide range of disabilities as a result of HIV and other chronic conditions.[27,28] As a result of further contribution of HIV to higher prevalence of chronic conditions, HIV needs to be viewed as a complex chronic disease and not just a single disease.[10]

Encouraging progress has achieved in many aspects of HIV care continuum particularly in high income countries including Canada (Fig 1), yet there is lack of progress in other ways. Despite virological control, HIV+ individuals continue to have a lower health-related quality of life compared to the general population.[29] Chronic HIV needs to be addressed like other chronic conditions following the model of chronic care where both health care team and individuals concerned need to share responsibilities.[15,30]

1.3 Chronic Disease Common Risk Factors

With increased life-expectancy of people with HIV, the effects of common risk factors for chronic diseases will also emerge. These include (i) modifiable behavioural risk factors; and (ii) metabolic risk factors.[31] Mental health challenges are also recognized in many chronic conditions especially HIV who also are experiencing the effects of loneliness and stigma.[32]

1.3.1 <u>Modifiable behavioural risk factors</u>

Modifiable risk factors are defined as behaviours or exposures that can change person's risk of chronic disease in a positive or negative direction.[33] Five key modifiable risk factors that can increase the risk of chronic conditions are tobacco use, physical inactivity, excess body weight, unhealthy diet, and alcohol consumption (in a harmful way).[33] Prevalence of all these risk factors continues to stay high for people all around the globe and in North America (Fig 2).[9] These factors combined make up more than 50% of the risk associated with chronic conditions.[34] The most recent report on health indicators of Canadians indicates that ~85% of Canadian adults have at least one the aforementioned risk behaviours[35] with more than 80% living a sedentary lifestyle and 70% pursuing an unhealthy dietary habit.

1.3.2 <u>Metabolic risk factors</u>

These are group of factors that elevate person's risk of developing health problems. The term "metabolic" is indicative of biomedical processes that occurs within the body. These factors vary from one condition to another; however, the key metabolic changes associated with elevated risk of chronic conditions are high blood pressure, hyperglycemia, and hyperlipidemia. Even though genetic make-up also has a role in modulation of metabolic factors[36] – classifying them as non-

modifiable – unhealthy behavioural risk factors are associated with increased metabolic changes.[37-39]

1.3.3 <u>Mental health challenges</u>

Intense, long-standing feelings (such as fear or guilt and resentment) are associated with chronic conditions as a result of demands made on the person and their families.[40,41] Although over three decades of HIV epidemic, the profile of mental health problems associated with HIV has much shifted to those associated with other chronic conditions,[42,43] there is an increasing acceptance that they have much more impact in HIV care.

Clinical work with people living with HIV has shown that fear of rejection or actual rejection, feeling of shame, and damaged identity and sexual life are salient concerns for people living with HIV.[44] Higher prevalence of depression and anxiety have also been shown to be a major barrier to HIV medication adherence.[45] Mental health issues, along with the underlying chronic condition, further affects physical health.[45,46] Attention to the mental health needs of people living with HIV has increasingly been recognised as a necessary component of HIV treatment and care.[47,48]

1.4 Chronic Disease Management

There is mounting evidence that shows management of a chronic disease goes beyond clinical management and involves addressing physical and mental health co-morbidities, patient's health outcomes, self-management, and quality of life. The Chronic Care Model (CCM),[49] a well-known and widely applied evidence-based framework for improving chronic care management, shows this holistic approach by taking into account the role of the health care system, community, and the person (Fig 3). Such a collaboration would be highly effective leading better

health outcomes, quality of care, and cost savings.[50] A challenge in applying this model to HIV is that the clinical care often focuses on the infectious disease component of HIV and the clinical team may be less well equipped for delivering care under the chronic disease model.[51,52] In this complex situation, improving self-management capabilities in people with HIV would be a potentially effective strategy.

1.4.1 Chronic disease self-management

To optimize care and resources according to the needs of the patients with chronic diseases, CCM operates within the context of the Kaiser Permanente (KP) model.[53] Adopting a population approach, KP model presents a delivery system by stratifying people and types of required services according to population needs. As shown in this model (Fig 4) The majority of the needs of people who are living with chronic conditions is manageable with self-care. While all components of the CCM model are mutually accountable for patients' health outcomes and quality of care, there is a growing body of literature that supports benefit of including self-management strategies to improve patient outcomes of chronic conditons.[54,55] In the context of HIV, self-management interventions in the forms of education programs,[30] peer led,[56] mobile health,[57] and symptom management[58] showed positive, though short-term, effects on improvement of patient's medical condition (lower viral load and improvement of CD4 cell count), physical health (using self-reported severity and frequency of symptoms), and medication adherence.

The concept of self-management support is based on i) delivering meaningful and relevant information to patients, help them set goals and make choices that lead to improved health outcomes over time; and ii) helping patients to acknowledge their central role in handling and managing their condition to the best of their capability. This is to help patients use the

6

information in a meaningful way and become the principal care givers and decision makers of their own condition.[59] Given the contribution of health behaviours to the consequences of chronic conditions, it is especially important to empower people to adopt healthy behaviours as this is perhaps what they have the most control over. According to the "ought implies can" principle,[60] people's responsibility over their actions (ought) holds true only if they could (can) have acted otherwise. In theory, it is not absolutely impossible for people who smoke, overly consume alcohol and unhealthy food, or neglect exercise to act otherwise. But the relevant question, as Schmidt[61] suggests his book chapter on chronic diseases, is "whether is it reasonably feasible for people to engage in healthy behaviours". For people to take personal responsibility for improving and managing their health condition, they need to receive information that they can understand and capability to make choices and set goals. Although self-management is a collaborative process between healthcare workers and patients, real-world have several constrains. While healthcare professionals try to address both acute and everyday needs of their clients, time and resource limitations might dominate patient' priorities.[62]

1.5 Goal-Setting – A Unique Aspect of Self-Management

Goal-setting occupies a pivotal place in self-management of chronic conditions. Systematic reviews of studies which evaluated self-management interventions in the context of chronic diseases have shown that integrating goal-setting as part of the intervention or adopting a patient-centered goal-setting approach increases likelihood of patients' progress towards achieving better health outcomes.[63-68] Patient-centered goals or patient-oriented goals are defined as goals set with patients actively engaged in the process through discussing goals, setting plans and evaluating their condition afterwards.[69] Yet, a recent review of studies on collaborative goal-setting has shown that patient involvement is only limited to identification of their concerns[65]

and older population seems even more deprived. Lawless et al.'s review reported of inconsistent practice approaches of healthcare providers regarding shared decision making and personalized care planning with older adults with some providers even differing from it.[70] Described by Rosewilliam et al. in their systematic review, this passivity seems to be influenced by both professionals' lack of time and patients' lack of enthusiasm to be actively involved.[71]

The literature on patients' experience with goal setting suggests that patients' unwillingness is often due to a mismatch between patients' and practitioners' priorities and attitudes.[72-74] A disease focused approach with emphasis on medical outcomes – the common practice during patients' consultations – rather than a person-driven goal-oriented plan leads to a fragmented approach which can prevent initiation of a self-management discussion.[75]

As chronic conditions require day-to-day management by the persons affected, goal-setting is a tool that encourages individuals' accountability, fosters their self-efficacy through development of active coping strategies, and allows them to gain some control over their condition with minimum or no supervision.[59]

1.6 The Process of Goal Formulation

People set their health-related goals according to their health reference points. Health reference point is "the level of mental, emotional, and physical health people believe possible or necessary to make the progress they seek".[76] Health reference point is formed by individuals' health status and circumstances and the "trade-offs" they are willing to take (Fig 5). Therefore, the health reference point originates from a person's inner and outer experiences and provides a personal health measure for a given timepoint in life.[76] Based on this self-evaluation, people can classify themselves as very healthy, healthy enough, or not healthy. Through this reflective and almost automatic process – whether done consciously or not – topics of the goals are identified.[77] This

insight is important in the context of chronic conditions because often times in practice goal formulation starts off by clinical assessment of patients – which might not necessarily include patients' input – and the output (formulated goal) reflects clinician's perspective of where patients need to get which might not be in line with what the patient wants or hope to achieve. As such, expected outcomes and certainly their metrics for measurements would not match.[78]

1.7 Goal Characteristics

Goal setting literature shows various interpretations of what constitutes a *good quality* goal. This subject has been reviewed in great detail by Siegert, Richard, and Levack in their book "Rehabilitation Goal Setting : Theory, Practice, and Evidence".[78] Authors mention that different approaches are due to application of different tools for the purpose of measuring goal-outcomes. For example, Goal Assessment Scale (GAS) has been designed for health professionals to assess patients' goal attainment.[79] Therefore, goals defined using GAS are formed objectively so that the observer can judge on patients' performance (the extent to which goal outcomes have been met).[80] Conversely, Canadian Occupational Performance Measure (COPM), is a patient reported outcome (PRO) measure where patients self-rate themselves on a 10-point scale.[81] Regardless of the tool being used for goal assessment, there is a wide consensus that goals should be specific, motivating (for the person), realistic (or achievable), challenging (or difficult), time-bound, in line with patient's situation, and broken into short-term steps (as oppose to long-term goal).[78] A named approach for goal formulation is the SMART approach coined by George T. Doran.[82] The acronym was defined as:

"Specific – targeting a specific area for improvement,

Measurable – Quantifying or at least suggesting an indicator of progress,

Assignable – Specifying who will do it,

Realistic – stating what results can realistically be achieved, given available resources,

Time-related – specifying when the result(s) can be achieved."

The SMART approach has been commonly used in the literature and different authors presented different interpretations of it. For example, the letter 'M' was used a 'motivating' in one version[83] and as 'measurable' in another version.[84] Similarly, the 'A' of the acronym was sometimes described as 'attainable'[83] and other times as 'activity-based.[85] To make goal formulation simple, Randall and McEwen[86] proposed that a good goal should be able to answer "who, will do what, under what condition, how well, and by when". This approach is very close to the SMART approach Doran proposed in 1981. The difference here, is that in the context of self-management, 'who' of the goal is the patient, 'will do what' should explain the activity that the patient is going to carry out to achieve the goal, 'how well' is a measure of performance expected from or set by the patient (to show how close or far the person is from the goal), and finally 'by when' captures the time frame within which the goal is going to be reached or re-evaluated.[86]

Plurality in goal setting approaches does not mean that one method of goal setting is necessarily more effective than the other.[78] Goal criteria are to increase task performance and as long as there is enough information in the formulated goal to answer the above-mentioned questions, the goal is a *good* goal.[87]

1.8 Goal specificity

According to Locke et al.,[88] goal specificity is "the degree of quantitative precision with which the goal is specified". Lining this definition with goal criteria, means the better the goal is formulated identified by presented goal criteria, the more specific the goal would be. This based on the assumption that goal specificity is a latent construct and fits within a formative

measurement model – where the items (goal criteria) forms the construct (goal specificity).[89]

Specificity of the goal has been viewed to be favorable to goal performance by:

i) increasing attention and in return action focusing on what needs to be done;[90] and

ii) stimulating task strategy (if-then) development.[91]

Therefore, it has been suggested that with goals being defined more specifically, individuals' chances of performance will increase due to less ambiguity in the evaluating the progress.[92] Less specified goals contain less information and less clarity of the course of actions allowing more outcomes to be treated as goal-based outcomes (achievement). Though these goals might improve person's confidence, they lead to a greater variance in performance and less progress towards the goal.[92]
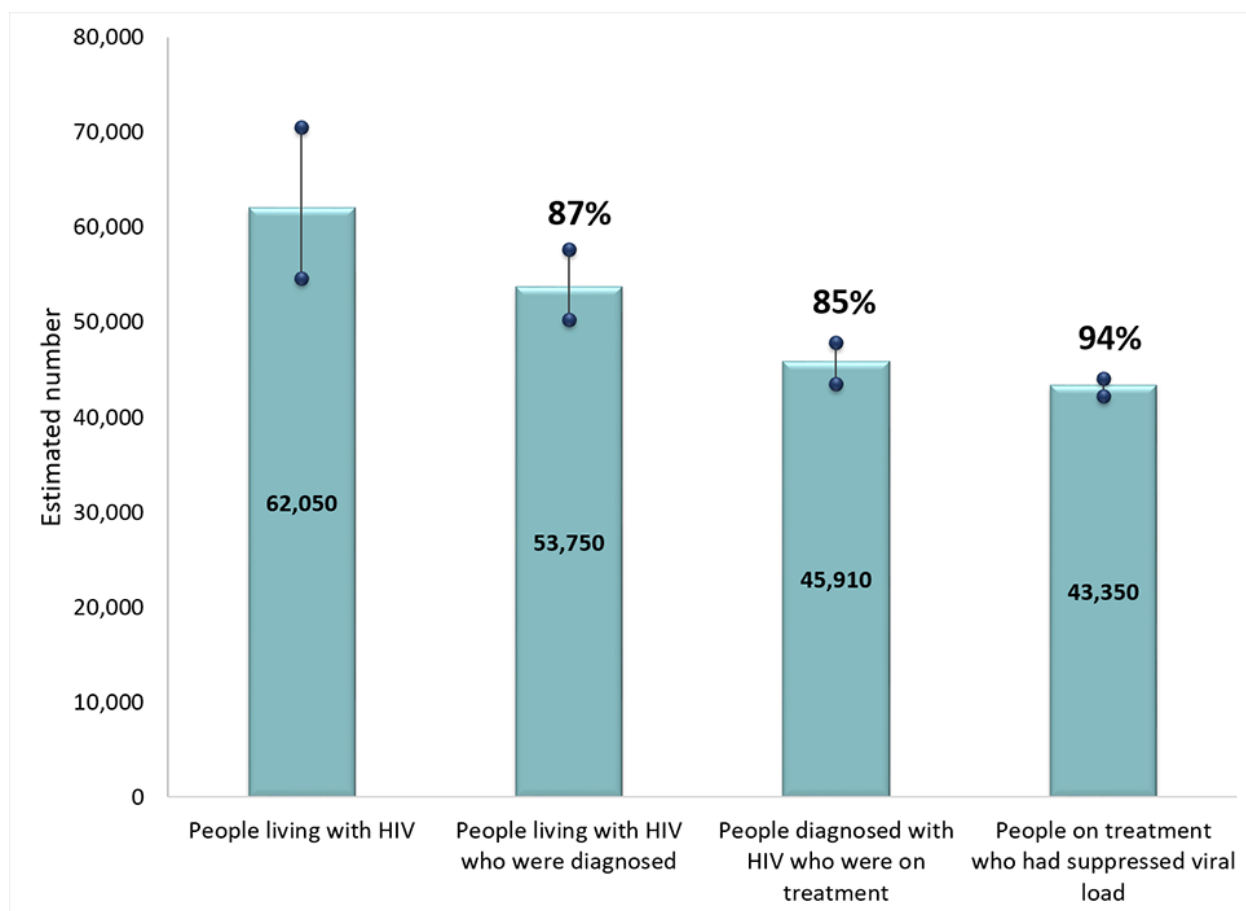
Figure 1 Estimates of HIV incidence, prevalence and Canada's progress on meeting the 90-90-90 HIV targets: Updated December 2020 (Public Health Agency of Canada).

Alcohol consumption per capita among adults aged 15 years and older (litres of pure alcohol)
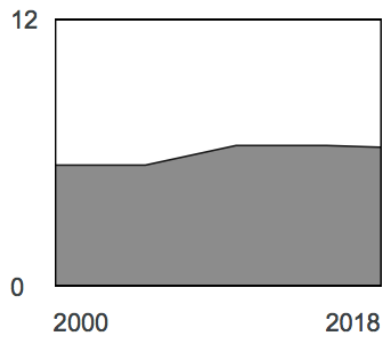
Prevalence of tobacco use among adults aged 15 years and older (%)
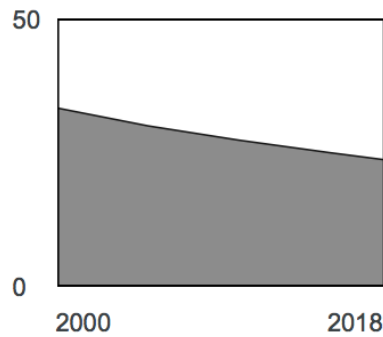
Prevalence of obesity among adults aged 18 years and older (%)
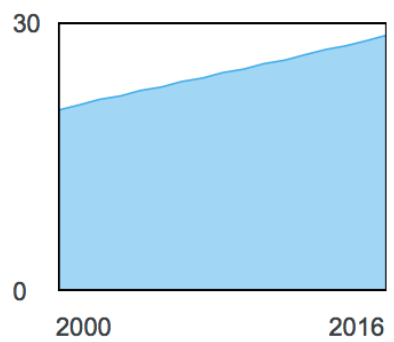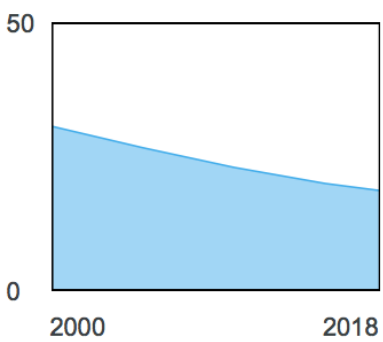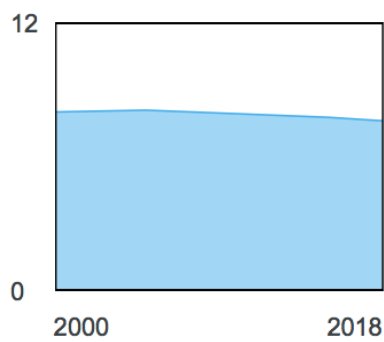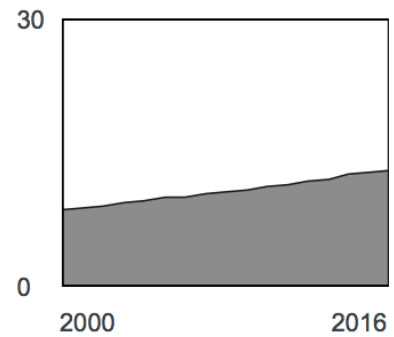
Note: Tobacco and obesity are age-standardized prevalences

Figure 2 Prevalence of three prevalent risk factors of chronic conditions from 2000 to 2018. The top row (grey boxes) presents the world prevalence. The bottom row (blue boxes) presents the trend for North America (World Health Organization, 2018).
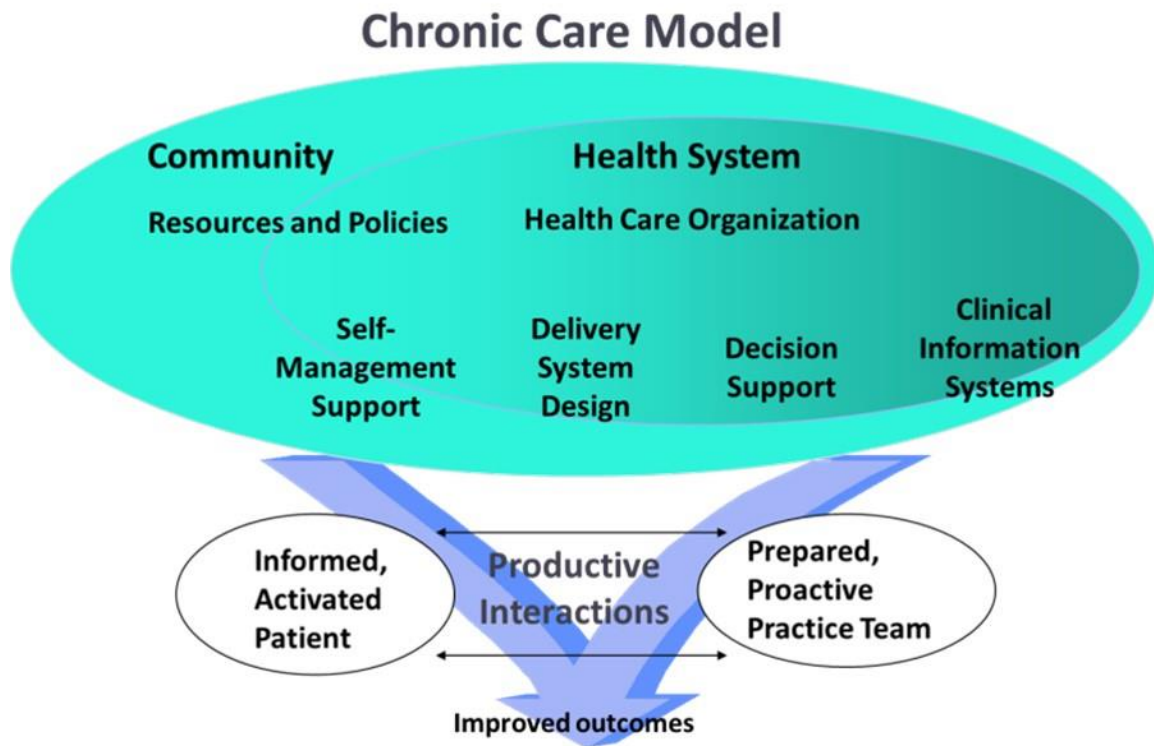
Figure 3 Elements of the Chronic Care Model (Glasgow et al., 2001).
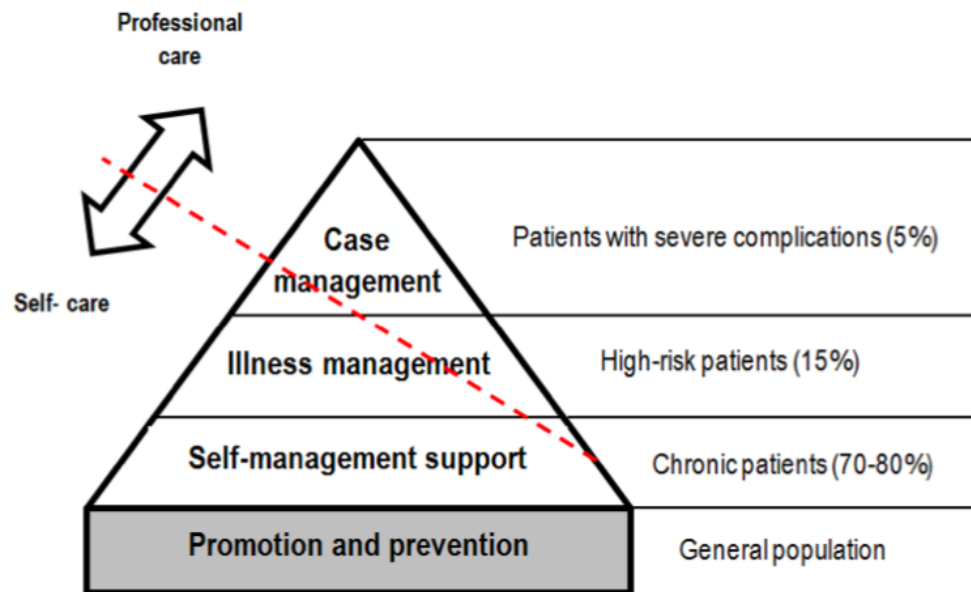
Figure 4 Kaiser Pyramid (Glasgow et al., 2001)
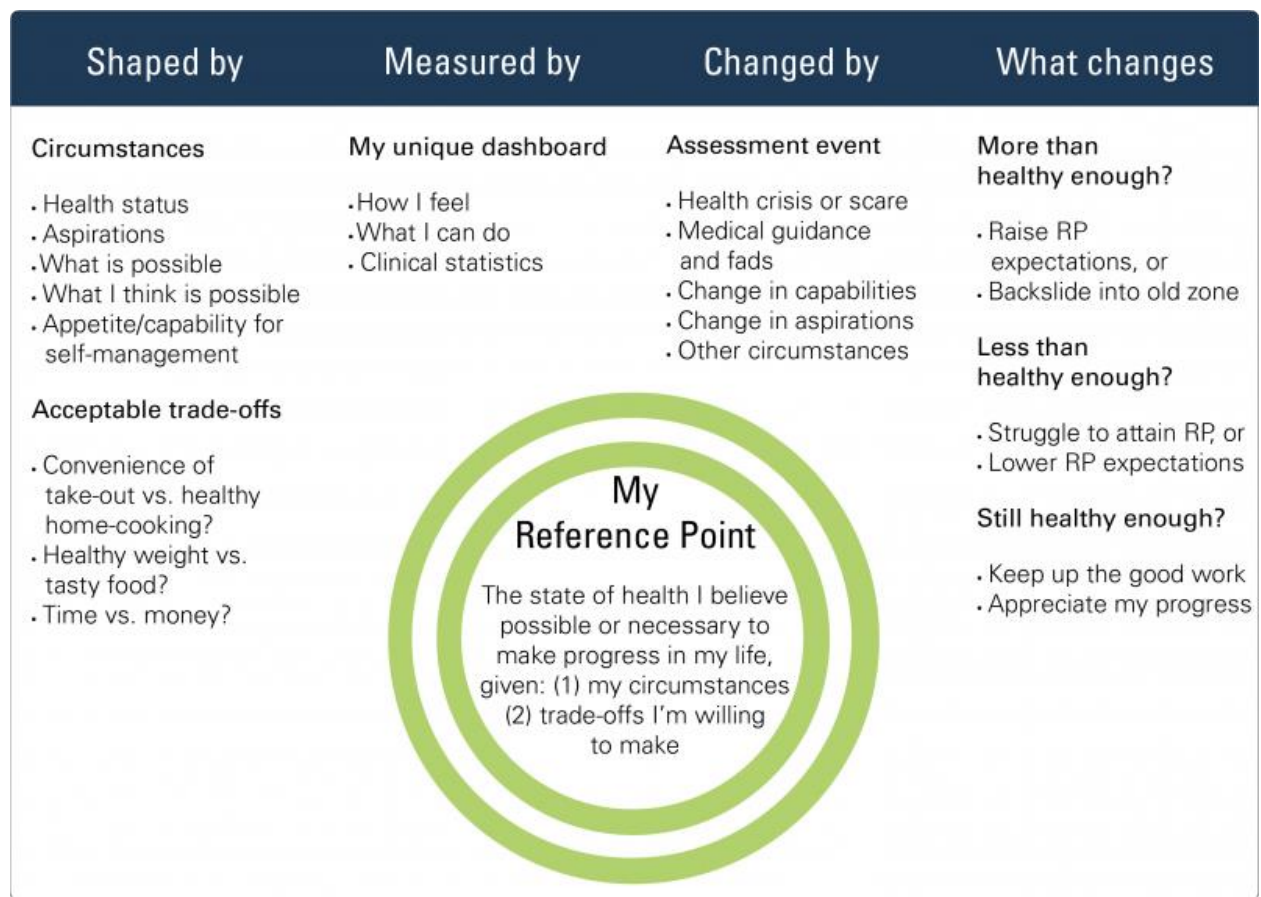
Figure 5 Health Reference Point (RP) formed by patients circumstances and their accepted trad-offs. Based on perception of RP patients decide for their desired change (i.e., goal) (Christensen Institute, 2017).

CHAPTER 2: Rationale Behind the Thesis

Both well-being and improved health-related quality of life (HRQoL) are the focus of chronic disease management. Common with other chronic conditions, chronic HIV management requires patients' adjustment to physically and emotionally taxing nature of their condition.[32] Improvement of HRQoL in chronic conditions is not an episodic care outcome; it happens over time and is mostly dependent on individuals' health behaviours and beliefs.[93] Appreciating that "individuals are active agents in their own environment",[94] it is believed that self-defined health improvement goals would help in driving progress towards the targeted behaviour.[95]

In clinical settings, guiding people to adopt healthy behaviors is overshadowed by patients' medical needs.[96] Improving patients' capabilities to take part in setting self-management goals has the potential to improve effective self-management as the goal setting process recognizes patients' wisdoms, preferences, and experiences which in return are likely to promote patients', engagement with care.[95] This practice is particularly important for public health applications where clinicians' input is absent. Personal health profiles with specific information about patients' health including behavioural indicators can provide patients with a reference point and could help with the uptake of healthy lifestyle behaviours. Explained by the mindset theory of action phases,[97] as people's needs increase, so as their wishes and desires to change, they feel forced to choose among their desires and turn them to goals. Based on this concept, it could be argued that a personalized health outcome profile, centered on health aspects of quality of life, can provide a goal setting opportunity by highlighting health-related needs.

The first component of the thesis was to review what is known about the contexts in which goal setting has been applied and its effectiveness in chronic conditions. The second component of the thesis was to develop a personalized health outcome profile specific for people living with HIV

and develop a way of measuring goal quality, which was missing from the literature. The development and application of text analytics in healthcare seemed a promising solution for this measurement need.

Designing and conducting a study to evaluate the effectiveness of using a personal profile to facilitate goal setting was depending on having a rigorous outcome. Finally, understanding the barriers to and enablers for acting on even well formulated goals, is seen as a way forward to optimize the self-management process.

2.1 Specific Objectives

The global aim of this thesis was to contribute evidence to the understanding of patient defined self-management goals in people living chronic condition such a HIV.

The specific objectives were as follows:

1- To estimate the magnitude of effect caused by goal setting on improvement of health outcomes and to identify the components of goal setting interventions and contexts in which they have been used or integrated into chronic disease management *(manuscript I)*.

2- To develop a personalized health outcome profile as a feedback tool and to evaluate its interpretability and usefulness for setting specific goals in people living with chronic conditions such as HIV *(manuscript II)*.

3- 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 *(manuscript III & IV – protocol & findings)*.

4- To identify the perceived barriers and enablers to acting on self-management goals among people living with HIV in Canada *(manuscript V)*.

CHAPTER 3 : Manuscript I

An Umbrella Review of the Literature on the Effectiveness of Goal Setting Interventions in Improving Health Outcomes in Chronic Conditions

Maryam Mozafarinia*[1,7], Kedar KV Mate[2,7], Marie-Josee Brouillette[3,7], Lesley K. Fellows[4], Bärbel Knäuper[5], and Nancy E. Mayo[1,6,7]

[1]Division of Experimental Medicine, [2]Chronic Viral Illness Service, [3]Department of Psychiatry, [4]Department of Neurology and Neurosurgery and Chronic Viral Illness Service, [5]Department of Psychology, [6]Department of Medicine and School of Physical and Occupational Therapy, [7]Center for Outcome research & Evaluation, McGill University, Montreal, Canada

Correspondence author:

Maryam Mozafarinia, RN, BScN, MScN,
Division of Experimental Medicine, Faculty of Medicine, McGill University &
Center for Outcome Research and Evaluation (CORE)
McGill University Health Centre Research Institute
5252 de Maisonneuve, Office 2C:13
Montréal, Québec, H4A 3S5
E-mail: maryam.mozafarinia@mail.mcgill.ca

Abstract

Background: Goal setting is known to drive behaviour change and has been extensively reported on in the chronic disease self-management literature. Aside from numerous experimental and observational studies, several meta-analyses and systematic reviews have provided additional evidence but report inconsistent results about the effectiveness of goal setting interventions on various health outcomes. With this amount of work, it is necessary to know whether still more primary studies are needed or could research in this field move forward. Umbrella reviews summarize the extent to which implementation recommendation is consistent by systematically appraising the available evidence across all reviews.

Objective: To identify the contexts in which goal setting has been used in chronic disease management interventions and to estimate the magnitude of its effect on improvement of health outcomes.

Methods: In this umbrella review the strength of evidence and extent of potential bias in the published systematic reviews of goal setting interventions in chronic conditions were summarized using AMSTAR2 quality appraisal tool, number of participants, 95% prediction intervals, and between-study heterogeneity. Components of goal setting interventions were also extracted.

Results: Seven publications and 17 meta-analysis models were identified, investigating 31 health outcomes. Of the 17 meta-analyses, two found suggestive evidence for goal setting on health outcomes. There was weak evidence for effects on five health outcomes (HbA1c, self-efficacy, depression health-related quality of life and physical activity), with the rest classified as non-significant. Half of the meta-analyses had low to moderate level of heterogeneity. None of the

calculated prediction intervals excluded the null value, suggesting that a substantial solo effect of goal setting will not be expected in future trials.

Conclusion: Goal setting by itself affects outcomes of chronic diseases only to a small degree. This is not an unexpected finding as changing outcomes in chronic diseases requires a complex and individualized approach. However, there was no evidence of harm. Implementing goal setting in a standardized way in the management of chronic conditions would seem to be a way forward. Incorporation of various goal setting components could contextualize how goal setting could help in areas that people living with chronic conditions grapple with.

Protocol registration: PROSPERO (CRD42020171531)

Keywords: Goal setting, Chronic diseases, AMSTAR 2, Umbrella review, Health outcomes

What is already known about the topic?

- Management of chronic disease – also known as "lifestyle-related diseases" – depends on promoting behaviour change.

- Goal setting is known to drive behaviour change.

- Goal setting is a circular process incorporating cooperation of the patients and healthcare professionals.

What this paper adds?

- This umbrella review demonstrates that goal setting by itself affects outcomes of chronic diseases only to a small degree; but there is no evidence of harm.

- Implementing goal setting in a standardized way in the management of chronic conditions would seem to be a way forward.

- Goal setting is a pragmatic intervention: Widely applicable, inexpensive, and unlikely to result in harm. Even a small effect can result in benefit for a large number of people when applied widely.

1. BACKGROUND

Chronic diseases are the leading cause of disability and premature death around the world.[1] Chronic diseases are also termed "lifestyle-related diseases" to emphasize the role of modifiable risk factors such as poor nutrition, lack of physical activity, tobacco use and excessive alcohol use.[2]. Chronic disease management depends on promoting behaviour change to achieve long-term adherence to preventive or therapeutic plans that can reduce metabolic and toxic effects of the risk factors and improve symptoms, function, and overall quality of life.[3,4]

Goal setting is known to drive behaviour change [5,6] and has been adopted by some quality assurance organizations as an accreditation standard for chronic care management programs.[7] Incorporation of goal setting within chronic care management helps healthcare providers maintain a holistic perspective on patients, including evaluating their skills and motivations. Goal setting is a circular process incorporating cooperation of the patients and healthcare professionals. Patient participation is important because goals could be formulated to address both what matters most to the patient and what is important for their health.[8]

Goal setting has been extensively reported on in the chronic disease self-management literature. Several randomized and non-randomized controlled trials (RCTs) and observational studies have reported a potential supportive effect of goal setting in improving some health outcomes and quality of life of people with chronic conditions. Meta-analyses and systematic reviews have provided additional evidence[9-15] but report inconsistent results about the effectiveness of goal setting interventions on various health outcomes within the context of chronic conditions. Systematic reviews are done with the aim of informing practice – by providing available evidence over a health-related issue more accessible for decision makers. When there are several systematic reviews or meta-analyses on a topic, the body of work may be too overwhelming to

23

be used by clinicians or other decision-makers.[16] This is the situation with goal setting in chronic disease management and whether do we still need to do more primary studies, or can we move on towards implementation. Umbrella reviews, however, summarize the extent to which implementation recommendation is consistent. Thereby, a systematic appraisal of the available evidence across all reviews would fill a gap by providing a transparent and rigorous synthesis of the existing evidence.

2. OBJECTIVES AND INCLUSION CRITERIA

The objective of this umbrella review was to identify the contexts in which goal setting has been used or integrated into chronic disease management interventions and to estimate the magnitude of its effect on improvement of health outcomes. This review tried to answer the following questions:

1- What are the contexts (i.e., health conditions, delivery setting, and types of goals) in which goal setting was used as an intervention – either stand-alone or as part of a complex intervention?

2- What are the components of the reviewed goal setting interventions?

3- What are the effects of goal setting on health outcomes?

2.1. Types of participants

Adults (>18 years of age) with a chronic condition. Both single and multiple chronic conditions were considered.

2.2. Intervention of interest

Goal setting either as a main intervention or integrated – as one of the main components – into a self-management intervention. Comparison was any intervention without goal setting, usual care, or time.

2.3. Setting

Both primary and non-primary health settings were considered.

2.4. Outcomes

All health-related outcome measures were considered. Health outcomes were classified based on an integrated model for classification of health outcomes integrating the International Classification of Functioning, Disability and Health (ICF) and the Wilson-Cleary Model of health-related quality of life.[17]

2.5. Types of studies

Systematic reviews (SR) of intervention studies of any design (e.g., experimental or observational design) were considered eligible as long as interventions were focused on goal setting in chronic conditions or self-management in chronic conditions with goal setting as one of the main components.

3. METHODS

This umbrella review used "A Measurement Tool to Assess Systematic Reviews (AMSTAR2)" reporting checklist. To authors knowledge, there is not yet a published (under preparation[18]) reporting guideline for umbrella reviews. However, descriptive documents related to reporting

umbrella reviews such as AMSTAR2 are available.The protocol for this umbrella review was registered with PROSPERO (CRD42020171531).

3.1. Data sources and search strategy

A multi-stage literature search was performed. First, a systematic search in five databases (MEDLINE (Ovid), PsychINFO (Ovid), EMBASE, CINAHL, and PubMed) were conducted by the first author in September 2019 for published systematic reviews of intervention studies on the effect of goal setting on health outcomes in chronic conditions, with no restriction on publication date. Language was restricted to English due to limitations in translation resources. The search terms used were "goal" or "goal planning" or "goal setting" or "care planning" and "chronic disease" or "chronic health condition". These terms were searched as keywords or subject headings depending on the database. The results were filtered for the category "review". The search terms and strategy for MEDLINE are provided in supplemental Appendix A.

Second, one author (MM) imported citations of all search studies into a reference management software package (EndNote) to remove duplicates. Titles and abstracts of the search results were examined by two authors (MM & KM) independently and clearly irrelevant studies were removed. In the third stage of the screening process, relevant reviews were obtained in full-text and screened against the inclusion and exclusion criteria. Full-text screening was conducted by two authors (MM & KM) independently. Discrepancies at each stage were resolved by discussion until consensus was reached. In cases where consensus could not be reached, a third reviewer (NEM) was consulted. Reference lists of the included studies were also checked for other potentially eligible reviews.

3.2. Data extraction

A data extraction form was developed based on the recommendation for conduct and reporting of an umbrella review.[19] Data were extracted by two reviewers (MM & KM) individually. In case of discrepancies, consensus was reached through discussion. Extracted data included: description of published reviews (objectives, number and type of included studies according to NICE guideline[20], type of chronic condition, intervention delivery setting, date range of included studies in the review, and quality appraisal tool for primary studies) and detailed description of interventions (type, delivery method, comparison, and outcome data). The health outcomes were categorized based on an integrated model for classification of health outcomes integrating the International Classification of Functioning, Disability and Health (ICF) and the Wilson-Cleary Model of health-related quality of life.[17]

Reviews were assessed for components of goal setting interventions based on the "Behavioural Change Technique Taxonomy" (BCTTv1).[21] This extensive taxonomy was developed by Michie et al.[21] in response to the CONSORT statement for provision of precise description on delivery of the intervention and especially "description of the different components of the interventions". Goal setting has been frequently reported as part of the behaviour change intervention package with inconsistent definitions and labels. Lack of well-defined interventions produce bias in evaluation of effectiveness of intervention. The bias here is because of uncertainties about intervention fidelity, as absence of such information makes it difficult to replicate or have confidence in the reported conclusion.[22,23] In systematic reviews, it is important to follow standardized definitions and labels for intervention components to help produce high-quality evidence across reviews.[23,24]

The BCTTv1 includes 16 broad groupings with a total of 93 behavioural change techniques (BCT). Each BCT represents an active component of a complex intervention and can be defined as "apparent, replicable, and irreducible component of interventions that are designed to change or redirect causal processes that regulate behaviour".[21] In this umbrella review, two groups of "goals and planning" and "feedback and monitoring" were used to extract active components of goal setting interventions. Together, these two groups contain 16 BCTs. Information on goal setting approaches in terms of goal assignment, documentation, level of participants' involvement, and topic and content of the goals were also extracted from the reviews.

3.3. Quality appraisal

Methodological quality of the included reviews was assessed using AMSTAR2 checklist.[25] AMSTAR2 is a critical appraisal tool for SRs that includes randomized or non-randomized studies of healthcare interventions. The checklist has 16 items of which 7 are considered critical domains such as possibility of publication bias or adequacy of literature search. However, lack of reporting on some of the critical items does not necessarily imply that the quality of the SR is critically low if the information can be inferred from the text. In this umbrella review, we used five of the critical items mentioned in the AMSTAR2 checklist. Published protocol and complete list of excluded studies were considered as non-critical as this was not a common practice for non-Cochrane reviews and only recently have been highlighted in the guidelines. As suggested by AMSTAR2 developers, we did not combine items for an overall score as it is important to consider the potential impact of inadequate report of each single item. However, we considered the total number of items met in the report of systematic reviews. Systematic reviews were assessed on each criterion on the AMSTAR2 checklist with a 'Y' indicating that the review provided enough information fulfilling the criteria and 'N' indicating that the criteria was not

met. If the item was partially met, it was rated as 'PY'. For reviews for which meta-analysis was not conducted, 'NM' was recorded. Rating for overall confidence in the results of the SRs were based on the presence or absence of flaws in critical domains. Reviews with more than one flawed critical domains (with or without weakness in non-critical domains) were rated as critically low and reviews with only one flawed critical domain were rated as low. Reviews with more than one flawed in non-critical domains were rated as moderate, and those with no or only one flaw in non-critical domain were rated as high. Quality appraisal was done by two reviewers individually and any disagreement, which occurred for 16% of the selected reviews, was resolved through discussion between the reviewers or arbitration by a third reviewer (NEM).

3.4. Reports on effects of the intervention

Quantitative findings for different health outcomes are limited to those reported in the reviews, with mean difference (MD) where outcomes were measured on the same scale and standard mean difference (SMD) with 95% confidence intervals (CI) where different scales were used in the collected studies. We avoided presenting primary research findings as per recommendations for summarizing SRs. For reviews where no pooled effect estimates were reported, narrative synthesis was provided.

3.5. Grading the evidence

For each meta-analysis, we extracted effect sizes together with the corresponding CI and the total number of participants for each outcome measure. We also estimated the 95% prediction interval (PI), which provides further information for between-study heterogeneity. Based on the reports of meta-analyses (observed values), a PI not only evaluates the full uncertainty around the summary estimate, but also provides a range for the treatment effect in a new study addressing

the same effect.[26] If the provided range excludes the null value (i.e., 0), it will be considered as

significant at the 5% level. Evidence from meta-analyses have been further stratified according

to a frequently applied classification system.[27-29]

- Strong (class I): number of cases>1000, $P<10^{-6}$, $I^2<50\%$, 95% confidence interval excluding null

- Highly suggestive (class II): number of cases>1000, $P<10^{-6}$, largest study with a statistically significant effect and class I criteria not met

- Suggestive (class III): number of case>1000, $P<10^{-3}$ and class I-II criteria not met

- Weak (class IV): $P<0.05$ and class I-III criteria not met

- Non-significant when $P>0.05$

We did not test for small study effects (i.e., Egger's test[30] for funnel plot asymmetry) as all the

meta-analysis models included fewer than 10 studies,[31,32] providing inadequate power to

distinguish chance from actual asymmetry. With small numbers of studies, even if there is no

evidence of funnel plot asymmetry, bias (including publication bias) cannot be excluded.

4. RESULTS

Figure 1 shows the PRISMA flowchart for the study selection process. A total of 832 review

studies were identified, of which 71 were excluded for duplication. After initial screening of the

titles and abstracts, another 761 studies were excluded due to not meeting the inclusion criteria.

A total of 46 studies remained for full-text review. Bibliographic search of the selected reviews

led to the addition of one more study for full-text review. Of the 47 selected SRs, 39 were

excluded mainly because goal setting interventions were unclear or not described in the reviews.

Of the 8 remaining reviews, one was an updated review[9] of a previous systematic review[33]

conducted by the same team. Twelve duplicate publications were found in these two reviews. As

the updated systematic review was more comprehensive, the older review was excluded. As a result, a total of 7 full-text systematic reviews met the inclusion criteria for the present umbrella review. The reference list for the 40 excluded studies can be seen in Appendix B.

4.1. Description of systematic reviews

The earliest systematic review was published in 2007 and the most recent appeared in 2019.[11,12,14] Five of the reviews had conducted meta-analyses. Together, the reviews included 125 individual studies of experimental or observational design. Since all SRs had an evaluative intent (i.e., to address the effectiveness of goal setting interventions), we followed the NICE guidelines to classify the study design of primary studies included in the reviews.[20] Of the 125 primary studies, 95 (76%) were experimental studies with a randomized controlled trial (RCT), clustered-RCT, or non-RCT design. The remaining 30 (24%) studies were observational with before-after, interrupted time-series, or cohort design. A total of 22,837 adult participants were enrolled in these studies. Countries where the original studies had been conducted were reported in six reviews. Most of the studies had taken place in the United States or Canada. The mean age of participants ranged from 33 to 83 years, reported in five of the reviews.[9,11,12,14,15] Gender distribution was reported in five reviews[9,11,12,14,15] and women predominated ($\geq$ 70%). A minimum of five databases were searched for relevant studies in all reviews. All reviews used a quality appraisal tool for assessing the quality of individual studies. Appendix C summarizes characteristics of the included SRs.

4.2. Methodological quality

Table 1 presents the quality of reporting for the systematic reviews using AMSTAR2 checklist. All reviews had clearly described research objectives/questions and inclusion criteria informing

their study selection. Four reviews followed registered/published review protocols[9,10,13,14] and the rest of the reviews did not demonstrate their work according to a written protocol or guide planned prior to conducting the review (i.e., registered in a registry such as PROSPERO or a published protocol in a journal). While without a published protocol judgment on review authors' adherence to or deviation from their original plan cannot be made, which increases the risk of selection bias in the reviews, this practice was not common for non-Cochrane reviews until recently.

All the SRs searched the reference list of the included primary studies and trial registries for other relevant papers, but not all searched for grey literature. Study selection was always done in duplicate, except in one review,[15] along with data extraction of the selected studies. In three reviews,[9,13,14] list of the excluded studies that were read in full text was provided. Justification for exclusion of studies after full-text review was mostly included in the PRISMA flowchart of all reviews.

Five of the reviews [9,10,12-14] had performed meta-analysis and where relevant investigated the cause of heterogeneity. Commentary on the potential impact of risk of bias on the primary study results was always provided in the discussion. The sources of funding for each included study in the reviews were not reported in all but two review.[9,13] Hence, there was no information on commercially or independently funded studies to evaluate whether or not the reported results are potentially in favour of the sponsor. In Levack et al.'s review, the majority of the primary studies were funded (62.5%) and of the remaining 37.5% of the studies, 4 (27%) were completed as PhD thesis, with unclear funding source for the rest. Similarly, in coulter et al.'s review, all included studies were funded except two which did not report.

In general, AMSTAR2 points for included SRs ranged from 12 to 16 with a median of 14 for reviews with meta-analysis. Based on AMSTAR2 checklist, the quality of the reviews were of moderate[10-12] to high[9,13,14] with only one review of low quality.[15] The two Cochrane reviews had a comprehensive summary of the results of the included studies.[9,13] It is important to note that as per AMSTAR guideline, critical nature of items could change as they are very much dependent on the design of the primary studies. For example, in the case of meta-analyses where the output is derived from more than one high quality randomized controlled trials, items such as adequacy of literature search, listing of excluded studies, or possibility of publication bias might be less important and not considered as critical.[25]

4.3. Findings

4.3.1   What are the contexts in which goal setting was used as an intervention?

In this umbrella review context refers to health conditions, delivery settings of interventions, and types of set goals. Chronic conditions studied in the included reviews were asthma, diabetes mellitus, arthritis, cardiovascular and renal diseases, chronic obstructive pulmonary disease, stroke and CNS injuries, musculoskeletal or chronic pain, and age-related disability. Three of the reviews [9,12-14] had populations with various health conditions termed as adults with acquired disability which included combinations of the abovementioned chronic conditions. Three reviews explored only one chronic conditions: Asthma,[11] diabetes mellitus [10] and stroke [15] (Appendix C). Goals were either lifestyle goals with the focus on improving physical activity[12,13] and physical function [9,15,34] or educational and psychological goals with the aim of symptom management or stabilization of the chronic condition.[10,11,13]

Delivery setting of the intervention in one reviews was non-primary care settings including outpatient clinics, rehabilitation centres, or local community settings.[12] In five other reviews,

delivery settings were mixed of non-primary and primary healthcare settings (i.e., hospitals, in-patient clinics).[9,10,13-15] One review did not report on the delivery setting of the intervention.[11] Follow-up time in the primary studies included in the reviews varied from a minimum of two-weeks to a maximum of 30 months. Appendix D provides a detailed description of the interventions reported in the included reviews.

4.3.2   What are the components of the reviewed goal setting interventions?

Table 2-A shows components of goal setting interventions based on the BCT taxonomy. Among the included reviews, one explicitly used the BCTTv1 to describe intervention components.[10] Another review reported on approaches to goal setting and strategies to enhance goal pursuit by using a detailed author-developed data extraction form based on popular goal setting approaches and theories.[9] Finally, a third review[13] only included studies that had a collaborative approach and used personalized care planning as a conceptual model to report on any steps of the collaborative process. In the rest of the studies, review authors did not follow a specific approach to report on characteristics of goal setting interventions.

We used the BCTTv1 and extracted components of goal setting interventions to the extent these were reported in the reviews. As shown in Table 4-A, a total of 10 BCTs were extracted as active components of goal setting interventions. Goals were mainly outcome goals (meaning goals were defined with at least one of following elements: context, frequency, duration, or intensity for the behaviour). Behavioural goals (i.e., setting goals in terms of a behaviour to be achieved) were included set in two review.[10,13] This pattern was expected because goals were defined according to research objectives of the primary studies which were mainly improving health outcomes as a consequence of a behaviour and not in terms of a behaviour to achieve. Action planning and/or problem solving were reported in five reviews.[9-13] Action planning was coded where: 1) a report

on encouraging participants to carry a plan and 2) some details on how to perform a behaviour was clearly explained in the intervention. Problem solving code was for any information on analyzing (by the interventionist) or prompting the individual to analyze the behaviour to identify barriers and thinking of facilitators. The majority of the reviews reported some sort of feedback and self-monitoring of the behaviour as active ingredients of the interventions.

Table 2-B shows how goal formulation was proceeded. Goal assignment was mainly collaborative even though a detail report was only provided in three reviews.[9,11,13] Goal documentation was only reported in two reviews[9,13] where participants either wrote down their goals or were given a goal setting form. Active participation in the goal setting process was reported in two review.[9,13] For the remaining five studies some levels of participation could be inferred based on individualized approach to goal setting.

Topics and content of the goals were reported in one reviews. In Bravata et al.'s review[12] on the effect of wearing a pedometer on physical activity, participants in the intervention groups received specific goals defining targeted number of steps per day or specific physical activity.

4.3.3   What are the effects of goal setting on health outcomes?

Table 3 provides a detailed summary of the quantitative findings reported in the systematic reviews. Outcome measures have been categorized based on an integrated model for classification of health outcomes[17] under seven rubrics: Biological function, activities and participation, symptom status, environmental factors, functional status, general health perception, and overall quality of life.[35] Narrative description of the outcomes are provided.

Five reviews reported on the effect of goal setting on biological function. A total of nine outcomes were assessed. Goal setting interventions were beneficial in lowering HbA1c,[10,13] body

mass index, and blood pressure.[12,13] Effects of goal setting on activities and participation were reported in three reviews with a total of four outcomes. Levack et al.[9] reported improvement in engagement in a rehabilitation program as measured by an increase in motivation, adherence to treatment, or involvement in rehabilitation sessions. However, there was evidence of high statistical heterogeneity in the observed outcomes. Similarly, in another review by Sugavanam et al.[15] more agreement in goal formulation, better recollection of their treatment goals, and improved task performance after rehabilitation were seen in the intervention group. However, the findings were based on one study with a small sample size (n=74) and of low quality.

Symptom status included two outcomes: asthma control and asthma severity. Findings were reported in one review[11] based on a total of 5 primary studies. Some improvement in controlling asthma symptoms and change of asthma status from severe to moderate or mild were noted in the intervention group. Environmental factors including duration of rehabilitation program and healthcare utilization were reported in two reviews.[11,14] A review by Smit et al.[14] on older adults with acquired disabilities showed no difference in duration of rehabilitation program for those who received goal setting interventions. In contrast, in another review on asthma[11], the total number of emergency or unscheduled visits and number of hospitalization were decreased for up to one year post-intervention.

Physical function, represented by physical activity, recovery, and step count, were reported in five reviews[9,10,12,14,15] of which two[12,15] reported an improvement in physical function A review of studies on the stroke population by Sugavanam et al.[15] reported improvement in recovery measured by performance and satisfaction scores of the Canadian Occupational Performance Measure (COPM). Bravata et al.'s[12] review on people with different chronic health conditions including neuromuscular disease showed that the intervention group which had a defined step

36

goal had 2004 more steps/day than the control group. The results were similar for both RCTs and observational studies.

General health perception in terms of self-efficacy, depression, and health-related quality of life (HRQoL) was reported in five reviews comprised of 48 primary studies[9-11,13,15]. In one review,[10] HRQoL was erroneously termed as "quality of life". Revised version of Diabetes Distress Scale (DSA) and Problem Areas in Diabetes Questionnaire (PAID) were used in the primary studies to measure the impact of diabetes (in terms of distress or emotions related to diabetes) on individuals' life which refers to HRQoL. All reviews collectively reported in favour of goal setting interventions leading to improvements in self-efficacy, depressive symptoms, and HRQoL. The quality of evidence, however, was moderate to low. Overall QoL, using 36-item short form survey (SF-36), was reported in one review with a total of 4 primary studies.[14] This finding was of low quality with evidence of high statistical heterogeneity. Overall, no change was reported in the overall QoL.

4.4. Grading the evidence

Table 4 shows a detailed description of the meta-analyses. Five reviews had conducted meta-analyses. Findings of meta-analyses showed small effect in favour of goal setting for HbA1c and systolic blood pressure (class III criteria). The evidence for the remaining meta-analyses was weak or non-significant.

The vast majority of primary studies in the meta-analyses had small or moderate sample sizes, most <500, four with sample sizes of >500 but <1000. Four meta-analyses had sample sizes of >1000. This is a common issue within meta-analyses of behavioural trials due to the challenges of participant recruitment and retention in clinical trials[36,37]. In a methodological paper on

sampling error in meta-analysis with small sample sizes, extensive simulation with different range of sample sizes (from 5 to 1000), number of included studies (from 5 to 50), and different extent of heterogeneity showed that estimated MDs and SMDs were almost unbiased with CI coverage of very close to 95%. However, for SMD, comparison of Cohen's *d* and Hedges' *g* showed that Cohen's *d* produced less bias in the estimated overall SMD [38]. In this umbrella review, all the included meta-analyses used MD or SMD (*d*) as the report of effect sizes. Based on this evidence, it might be inferred that the reported effect sizes of the meta-analyses could be very close to the true effect size; but due to the low quality of the primary studies – indicating further existence of bias – discounting the effect of small sample sizes would not be wise.

In all the meta-analyses, the 95% prediction intervals included the null value, showing that although on average some improvements in the health outcomes might be due to the effect of goal setting interventions, this might not always be the case in specific settings.

Of the 17 meta-analyses, no levels of heterogeneity were shown in five, low to moderate in four, and high in eight. Uncertainty in heterogeneity estimates was reflected in by wide 95%CI of the I^2. Effect estimates calculated by meta-analyses for almost all of the outcome measures were small to medium (i.e., SMD <0.5).

4. DISCUSSION

This umbrella review of 7 published systematic reviews covering 125 primary studies and 31 health outcomes found small effect of goal setting on improvement of certain health outcomes. Although the quality of evidence is moderate to low. This finding arose from the five reviews providing results from 17 meta-analyses. The remaining two reviews provided only a narrative analysis of the effect of goal setting on health outcomes which could not be used to infer effect.

Half of the meta-analyses had very low to some moderate level of heterogeneity despite the magnitude of the effect estimates.

Of the seven reviews, six were rated as high or moderate quality using the AMSTAR2 quality appraisal tool. One review was rated as low quality as risk of bias was not clearly reported in interpretation of results. some other non-critical quality gaps were lack of justification for excluded studies (57%) followed by no published protocol (43%). This may introduce a selective reporting bias. On average, the quality of primary studies as reported in the reviews was low to moderate. The primary trials in the included SRs suffered from publication bias and a range of methodological limitation such as missing data and short length of follow-ups.

In this umbrella review, we targeted the 16 behaviour change techniques under "goals and planning" and "feedback and monitoring" as our goal was to extract active goal setting components of the interventions. Even though interventions were limited in number of BCTs, potential overlap between BCTs could be concluded despite no clear report. As collaborative and individualized approach was dominant for goal assignment, some levels of participation could be inferred. However, tailoring interventions to participants' needs might not necessarily equate to active participation in goal setting.

Our umbrella review is limited to what has been investigated, published, and systematically reviewed and meta-analyzed in the SRs. The number of studies included in the meta-analyses ranged from 3 to 9 (median of 4.5). Given the limited number of studies, sensitivity analysis was not always applicable, although potential risk of bias was mostly addressed adequately in the discussion sections of the reviews. None of the calculated prediction intervals excluded the null value, suggesting that a substantial effect of goal setting (as an independent intervention) will not be expected in future trials.

Lack of substantial effect does not translate into no effect. One reason that could contribute to the observed low effect sizes is the absence of minimal clinically importance difference (MCID) metrics for different outcomes. For example, effect of goal setting on physical activity measured by step count[12] was shown by a mean difference of 2004 steps/day between intervention and control groups (random assignment to goal setting and no goal setting groups) where participants' baseline was in a range of 2140 to >10,000 steps/day. The calculated prediction interval for this outcome was 599 to 3408. This means that future studies are likely to be in this range. This may not be a large effect size but it is clinically meaningful in the context of chronic health conditions such as multiple sclerosis,[39] stroke,[40] and chronic obstructive pulmonary disease (COPD).[41,42] In addition, goal setting is a pragmatic intervention; therefore, it is widely applicable, inexpensive, and unlikely to result in harm. Even a small effect can result in benefit for a large number of people when applied widely. An example of a small effect having widespread benefits comes from a review by Tudor-Locke et al. [43] on "how many steps/day are enough". This review reported that expected steps/day for chronic conditions varies from 1200 to 8800 steps/day, taking into consideration compromised ability and endurance of people living with chronic conditions. They further suggested an "extra 3000 steps/day in bouts of more than 10 minutes, above and beyond activities of daily living" as a public health guidelines for older adults and those with chronic conditions. This translates into approximately 5500 steps/day considering a "basal activity level" (i.e., <2500 steps/day) which also appears to be associated with higher HRQoL scores.[43] Thereby, considering participants' baseline, an observed mean difference of 2004 steps/day shown in one of the reviews is a good progress towards the targeted outcome of extra 3000 steps/day.

The findings of this umbrella review might be discordant with the strong belief in the literature regarding the potential effect of goal setting on improvement of chronic disease behaviours and health outcomes. However, this belief seems to be based on a limited number of small primary studies. The link between goal setting and health outcomes is potentially weak because the proximal outcome of goal setting is behaviour change. While behaviour changes are linked to health outcomes, they are far from sufficient. In addition, there is wide variability in the "who" and the "how" of goal setting that will dilute a summary estimate of effect. Health behaviours are also complex. This means that goals set for health outcomes will require a complex action plan that carefully considers all the causal factors leading to the specific outcome. Otherwise, rushing to evaluate the outcome rather than focusing on the evaluation of sub-behaviours is likely to lead to disappointing results.

Goal setting needs to be considered and evaluated at the behaviour or action plan stage because: (i) this stage is more under the person's control; (ii) better reflects the person's effort, persistence, and concentration rather than outside influences; and (iii) success in this stage would enhance maintenance of the behavior which ultimately helps with achievement of targeted health outcomes. As highlighted almost three decades ago by Strecher et al.,[44] the question is not whether goal setting should be used; rather it is about applying it consistently and systematically with regard to specific non-complex tasks. Not all reviewed studies had a detailed description of active ingredients of goal setting interventions.

5. CONCLUSION

Goal setting by itself affects outcomes of chronic diseases only to a small degree. This is not an unexpected finding as changing outcomes in chronic diseases requires a complex and individualized approach.[3,4] However, there was no evidence of harm. Implementing goal setting

in a standardized way in the management of chronic conditions would seem to be a way forward. Studying the implementation of goal setting would provide needed evidence for comparative effectiveness which is information needed to personalize interventions.

Goal setting is a multi-component intervention where the components act as a system in making progress towards the set goals. Self-management in chronic conditions goes hand in hand with mastering goal setting and action planning. Yet, there are still questions that could be addressed by evaluating the implementation of goal setting. Incorporation of various goal setting components while actively engaging patient and/or their care givers in the process could contextualize how goal setting could help in areas that people living with chronic conditions grapple with.

Conflict of Interest: The author(s) declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Reference

1. CDC (Cent. Dis. Control Prev.). Chronic disease prevention and health promotion: chronic disease overview. National Center for Chronic Prevention and Health Promotion. https://www.cdc.gov/chronicdisease/pdf/nccdphp-overview-508.pdf. Published 2018. Accessed August 2020.

2. World Health Organization. WHO global report: preventing chronic diseases: A vital investment. World Health Organization. https://www.who.int/chp/chronic_disease_report/en/. Published 2005. Accessed August 2020.

3. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. *JAMA.* 2002;288(14):1775-1779.

4. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the chronic care model, Part 2. *JAMA.* 2002;288(15):1909-1914.

5. Bodenheimer T, Handley MA. Goal-setting for behavior change in primary care: an exploration and status report. *Patient Educ Couns.* 2009;76(2):174-180.

6. Coleman MT, Newton KS. Supporting self-management in patients with chronic illness. *Am Fam Physician.* 2005;72(8):1503-1510.

7. National Committee for Quality Assurance. Patient-centered medical home (PCMH). https://www.ncqa.org/programs/health-care-providers-practices/patient-centered-medical-home-pcmh/. Published 2011. Accessed August 2020.

8.   Lenzen SA, Daniels R, van Bokhoven MA, van der Weijden T, Beurskens A. Setting

        goals in chronic care: Shared decision making as self-management support by the family

        physician. *Eur J Gen Pract.* 2015;21(2):138-144.

9.   Levack WMM, Weatherall M, Hay-Smith EJC, Dean SG, McPherson K, Siegert RJ. Goal

        setting and strategies to enhance goal pursuit for adults with acquired disability

        participating in rehabilitation. *Cochrane Database Syst Rev.* 2015(7).

        doi:10.1002/14651858.CD009727.pub2.

10.   Fredrix M, McSharry J, Flannery C, Dinneen S, Byrne M. Goal-setting in diabetes self-

        management: A systematic review and meta-analysis examining content and

        effectiveness of goal-setting interventions. *Psychol Health.* 2018;33(8):955-977.

11.   Liao Y, Gao G, Peng Y. The effect of goal setting in asthma self-management education:

        A systematic review. *Int. J. Nurs. Sci.* 2019;6(3):334-342.

12.   Bravata DM, Smith-Spangler C, Sundaram V, et al. Using pedometers to increase

        physical activity and improve health: a systematic review. *JAMA.* 2007;298(19):2296-

        2304.

13.   Coulter A, Entwistle VA, Eccles A, Ryan S, Shepperd S, Perera R. Personalised care

        planning for adults with chronic or long-term health conditions. *Cochrane Database Syst

        Rev.* 2015(3):CD010523.

14.   Smit EB, Bouwstra H, Hertogh CM, Wattel EM, van der Wouden JC. Goal-setting in

        geriatric rehabilitation: a systematic review and meta-analysis. *Clin Rehabil.*

        2019;33(3):395-407.

15.   Sugavanam T, Mead G, Bulley C, Donaghy M, van Wijck F. The effects and experiences of goal setting in stroke rehabilitation - a systematic review. *Disabil Rehabil.* 2013;35(3):177-190.

16.   Fusar-Poli P, Radua J. Ten simple rules for conducting umbrella reviews. *Evid. Based Ment. Health.* 2018;21(3):95-100.

17.   Valderas JM, Alonso J. Patient reported outcome measures: a model-based classification system for research and clinical practice. *Qual Life Res.* 2008;17(9):1125-1135.

18.   Pollock M, Fernandes RM, Pieper D, et al. Preferred Reporting Items for Overviews of Reviews (PRIOR): a protocol for development of a reporting guideline for overviews of reviews of healthcare interventions. *Syst. Rev.* 2019;8(1):335.

19.   Aromataris E, Fernandez R, Godfrey CM, Holly C, Khalil H, Tungpunkom P. Summarizing systematic reviews: methodological development, conduct and reporting of an umbrella review approach. *Int J Evid Based Healthc.* 2015;13(3):132-140.

20.   National Institute for Health and Clinical Excellence. The guidelines manual. London: National Institute for Health and Clinical Excellence. www.nice.org.uk. Published 2012. Accessed August 2020.

21.   Michie S, Richardson M, Johnston M, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. *Ann Behav Med.* 2013;46(1):81-95.

22.   Duncan E, O'Cathain A, Rousseau N, et al. Guidance for reporting intervention development studies in health research (GUIDED): an evidence-based consensus study. *BMJ Open.* 2020;10(4):e033516.

23. Hoffmann TC, Glasziou PP, Boutron I, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *Br. Med. J.* 2014;348:g1687.

24. Hoffmann TC, Walker MF, Langhorne P, Eames S, Thomas E, Glasziou P. What's in a name? The challenge of describing interventions in systematic reviews: analysis of a random sample of reviews of non-pharmacological stroke interventions. *BMJ Open.* 2015;5(11):e009051.

25. Shea BJ, Reeves BC, Wells G, et al. AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. *Br. Med. J.* 2017;358:j4008.

26. Borenstein M, Higgins JP, Hedges LV, Rothstein HR. Basics of meta-analysis: I(2) is not an absolute measure of heterogeneity. *Res Synth Methods.* 2017;8(1):5-18.

27. Belbasis L, Bellou V, Evangelou E, Ioannidis JP, Tzoulaki I. Environmental risk factors and multiple sclerosis: an umbrella review of systematic reviews and meta-analyses. *Lancet Neurol.* 2015;14(3):263-273.

28. Bellou V, Belbasis L, Tzoulaki I, Evangelou E, Ioannidis JP. Environmental risk factors and Parkinson's disease: an umbrella review of meta-analyses. *Parkinsonism Relat Disord.* 2016;23:1-9.

29. Bellou V, Belbasis L, Tzoulaki I, Middleton LT, Ioannidis JP, Evangelou E. Systematic evaluation of the associations between environmental risk factors and dementia: An umbrella review of systematic reviews and meta-analyses. *Alzheimer's Dement.* 2017;13(4):406-418.

30.   Egger M, Smith GD, Schneider M, Minder C. Bias in meta-analysis detected by a simple, graphical test. *Br. Med. J.* 1997;315(7109):629-634.

31.   *Cochrane Handbook for Systematic Reviews of Interventions version 6.0 (updated July 2019).* www.training.cochrane.org/handbook: Cochrane; 2019.

32.   Sterne JAC, Sutton AJ, Ioannidis JPA, et al. Recommendations for examining and interpreting funnel plot asymmetry in meta-analyses of randomised controlled trials. *Br. Med. J.* 2011;343:d4002.

33.   Levack WM, Taylor K, Siegert RJ, Dean SG, McPherson KM, Weatherall M. Is goal planning in rehabilitation effective? A systematic review. *Clin Rehabil.* 2006;20(9):739-755.

34.   Smit EB, Bouwstra H, Hertogh CM, Wattel EM, van der Wouden JC. Goal-setting in geriatric rehabilitation: a systematic review and meta-analysis. *Clin Rehabil.* 2019;33(3):395-407.

35.   Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *Jama.* 1995;273(1):59-65.

36.   Institute of Medicine (US). Recruitment Challenges in Clinical Trials for Different Diseases and Conditions. National Academies Press (US). Public Engagement and Clinical Trials: New Models and Disruptive Technologies: Workshop Summary Web site. https://www.ncbi.nlm.nih.gov/books/NBK92105/. Published 2012. Accessed.

37.   Mayo NE. Understanding analyses of randomized trials. In: John C. Balilar III, Hoaglin DC, eds. *Medical uses of statisitics, 3rd edition.* Hoboken, New Jersey: John Wiley & Sons, Inc; 2009:195-237.

38. Lin L. Bias caused by sampling error in meta-analysis with small sample sizes. *PLoS ONE.* 2018;13(9):e0204056.

39. Dlugonski D, Pilutti LA, Sandroff BM, Suh Y, Balantrapu S, Motl RW. Steps per day among persons with multiple sclerosis: variation by demographic, clinical, and device characteristics. *Arch Phys Med Rehabil.* 2013;94(8):1534-1539.

40. Fini NA, Holland AE, Keating J, Simek J, Bernhardt J. How Physically Active Are People Following Stroke? Systematic Review and Quantitative Synthesis. *Phys Ther.* 2017;97(7):707-717.

41. Heleen D, Chris B, Miek H, et al. The Minimal Important Difference in Physical Activity in Patients with COPD. *PLoS ONE.* 2016;11(4). doi:10.1371/journal.pone.0154587.

42. Teylan M, Kantorowski A, Homsy D, Kadri R, Richardson C, Moy M. Physical activity in COPD: Minimal clinically important difference for medical events. *Chron Respir Dis.* 2019;16:147997311881642.

43. Tudor-Locke C, Craig CL, Aoyagi Y, et al. How many steps/day are enough? For older adults and special populations. *Int. J. Behav. Nutr. and Phys. Act.* 2011;8(1):80.

44. Strecher V, Seijts G, Kok G, et al. Goal Setting as a Strategy for Health Behavior Change. *Health Educ Q.* 1995;22:190-200.

Figure 1 PRISMA Flow Diagram

Identification

Systematic reviews identified in
- CINAHL (n = 13)
- MEDLINE (n = 124)
- EMBASE (n = 51)
- PsychINFO (n = 3)
- PubMed (n = 641)

Screening

Systematic reviews identified through database searching (n = 832)

Duplicates removed (n = 71)

Records screened based on title and abstract (n = 761)

Records excluded based on title and abstract (n = 714)

Eligibility

Additional records identified in the reference lists (n = 1)

Full-text systematic reviews assessed for eligibility (n = 46)

Full-text systematic reviews excluded, with reasons (n = 40)

- Not in English (1)
- Full text not available (1)
- Objectives did not meet the inclusion criteria; unclear or no components of goal setting was described in the reviews (34)
- SR with 12 duplicate publications with an updated SR conducted by the same authors (1)
- Combination of self-management strategies focused on education with written action plans (inference on goal setting was not possible) (3)

Included

Systematic reviews included in umbrella review (n = 7)

Table 1 Information on appraisal of included reviews

AMSTAR II items/ reviews	Bravata et al. (2007)	Sugavanam et al. (2012)	Levack et al. (2015)	Coulter et al. (2015)	Fredrix et al. (2018)	Liao et al. (2019)	Smit et al. (2019)
Research question & inclusion criteria (PICO)	Y	Y	Y	Y	Y	Y	Y
Review methods/protocol	N	N	Y	Y	Y	N	Y
Selection of study designs	Y	Y	Y	Y	Y	Y	Y
*Comprehensive literature review search	Y	PY	Y	Y	PY	PY	PY
Study selection in duplicate	Y	N	Y	Y	Y	Y	Y
Data extraction in duplicate	Y	Y	Y	Y	Y	Y	Y
List of excluded articles with justification	N	N	Y	Y	N	N	Y
Included studies in adequate details	Y	Y	Y	Y	Y	Y	Y
*Assessing risk of bias (RoB)	PY	Y	Y	Y	Y	Y	Y
Source of funding for individual studies included	N	N	Y	Y	N	N	N
*Meta-analysis/appropriate methods for statistical combination of results	Y	NM	Y	Y	Y	NM	Y
Meta-analysis/potential impact of RoB	Y	NM	Y	Y	Y	NM	Y
*RoB in interpreting/discussing the results	Y	N	Y	Y	Y	Y	Y
Discussion on heterogeneity observed	Y	Y	Y	Y	Y	Y	Y
*Adequate investigation on publication bias	Y	NM	Y	Y	Y	NM	Y
Potential source of conflict of interest	Y	Y	Y	Y	Y	Y	Y
Rating overall confidence in the results of the review (# of items met out of 16 & out of 13 for No Meta-analyses)	Moderate (12)	low (7)	High (16)	High (16)	Moderate (13)	Moderate (9)	High (14)

Abbreviations: PICO: Population, `intervention, Comparison, Outcome; RoB : Risk of Bias; NM : No Meta-analysis; PY: Partially Yes

Low: one critical domain not met with or without non-critical weakness; **Moderate:** more than one non-critical domain not met; **High:** no or one non-critical weakness

*Items noted with star and shaded in grey are critical domains considered for overall rating.

Table 2-A Components of "goal setting interventions" based on the BCT taxonomy

Author (year) number of included studies in the review BCT	Bravata et al. (2007) n=26	Coulter et al. (2015) n=19	Levack et al. (2015) n=39	Fredrix et al. (2018) n=14	Liao et al. (2019) n= 9
Goal setting (behaviour)		52.6		83.3	
Goal setting (outcome)	84.6	47.4	61.5	25.0	
Action planning (including implementation intentions)	*	100.0	78.4$^\Psi$	58.3	88.9
Problem solving/ coping planning	38.5%	100.0	*	66.7	88.9
Review behaviour goals		15.8		33.3	
Review outcome goals	92.3	*	41	41.7	
Behavioural contract		36.8			
Commitment		21.0	5.1		
Feedback on behaviour	100.0	26.3	7.7	*only biofeedback was given (33.3)	22.2
Self-monitoring of behaviour	92.3	*	10.2	16.6	11.1

Notes: Only BCTs which were reported in the SRs are included in the table. Numbers are in percentage.

*Cells with star mean no clear report but possibility of potential overlap between those BCTs and the ones reported in the SR.

Ψ In two studies included in this SR, action planning was irrelevant as the aim of the studies were to enhance recall of goals over a period of time.

Studies were not included if none of the BCTs were reported or could inferred from the paper: Sugavanam et al. (2012) & Smit et al. (2019) .

Table 2-B Goal setting approaches

Author (year) / Goal setting approach	Bravata et al. (2007)	Coulter et al. (2015)	Sugavanam et al. (2015)	Levack et al. (2015)	Fredrix et al. (2018)	Liao et al. (2019)	Smit (2019)
Goal assignment — Prescribed	√		√	15.4%		11.1%	√
Self-driven					√		
Collaborative	√	100%	√	79.5%	√	77.8%	√
Unclear			?	5.1%			?
Goal documentation	?	36.8%	?	√	?	?	?
Participant involvement	±	100%	?	79.5%	?	±	?
Behaviour/outcomes targeted	Number of steps/day and/or specific physical activity	Metabolic and behavioural outcomes	?	Body function, activity limitations, work performance, dietary behaviour, pain management, or mix of behaviours (61.5%)	?	?	?

Notes: Percentages present proportion of primary studies in the systematic review that reported on specific approach for goal setting.

√ means a general (not detailed) report on goal assignment was provided or could be inferred from characteristics of interventions provided in the reviews.

? means no clear report was provided in the systematic reviews.

± means somewhat involvement (based on collaborative goal assignment) but no clear report.

Table 3 Summary of the quantitative findings reported in the reviews for effect of goal setting on health outcomes

	Outcome measures	Author (year)	Number of studies/participants	Analytic metric (or meta-analytic where relevant)	Results/findings (as reported in the reviews)	Quality of the evidence for primary studies[*]
Biological function	Pulmonary function test	Liao et al. (2019)	2/ 120	Not reported	No change	Low
	HbA1c	Fredrix et al. (2018)	5/ 931	MD (95% CI)	↓ by 0.22 from baseline (-0.40 to -0.04, $P = 0.01$)	Low/very low
	body weight	Fredrix et al. (2018)	3/ 596	MD (95% CI)	No change	Very low
	Body structure and body function	Levack et al. (2015)	5/ 235	MD (95% CI)	3 of 5 studies reported no difference between the groups 2 of 5 studies reported an improvement in body functioning (muscle endurance and ventilation oxygen) both at baseline and end of treatment	Very low
	HBA1c	Coulter et al. (2015)	9/1916	MD (95% CI)	↓ by 0.24 from baseline (-0.35 to -0.14, $P = 0.01$)	Moderate
	Systolic blood pressure	Coulter et al. (2015)	6/1200	MD (95% CI)	↓ by 2.64 from baseline (4.47 to -0.82, $P = 0.01$)	Moderate
	BMI	Bravata et al. (2007)	18/ 562	MD (95% CI)	↓ by 0.38 from baseline (-0.05 to -0.72, $P<0.3$)	Moderate
	Systolic blood pressure	Bravata et al. (2007)	12/468	MD (95% CI)	↓ by 3.8 from baseline (-1.7 to -5.9, $P<0.01$)	Moderate
	Diastolic blood pressure	Bravata et al. (2007)	12/468	MD (95% CI)	↓ by 0.3 from baseline (0.02 to -0.46, $P = 0.01$)	Moderate
	Lipid profile	Bravata et al. (2007)	7/ 192	MD (95% CI)	No change	Moderate
	Fasting glucose	Bravata et al. (2007)	7/ 211	MD (95% CI)	No change	Moderate
Activities & participation	Self-monitoring of blood glucose	Fredrix et al. (2018)	1/ not clear	Not reported	No change	Very low
	Participation	Levack et al. (2015)	4/ 254	MD (95% CI)	↑ in participation in only 1 out of 4 studies based on improvement in work performance 16.0 (4.22 to 27.78) No change reported in other studies	Very low
	Engagement in rehabilitation (motivation, involvement, & adherence)	Levack et al. (2015)	9/ 369	SMD (95% CI)	↑ in engagement 0.30 (-0.07 to 0.66)	Very low
	Engagement in rehabilitation	Sugavanam et al. (2012)	1/ 74	Percentage	Intervention group compared to control group had more agreement in goal formulation (82% vs. 27%), had better recollection of their treatment goals (72%	Low

					vs. 36%), & managed more tasks compared to before rehab (75% vs. 9%)
Symptom status	Asthma control	Liao et al. (2019)	4/ 634	Not reported	↑ in ACQ score for intervention group compared to control group in 3 out of 4 studies	Low
	Asthma severity	Liao et al. (2019)	1/ 50	Not reported	↑ Change from severe to not severe (i.e., moderate or mild) category for intervention group	Low
Environmental factors	Healthcare utilization	Liao et al. (2019)	3/ 535	Not reported	↓ # of ED & unscheduled visits and # of hospitalization in 2 out of 3 studies for up to 1-year post intervention	Low
	Duration of rehabilitation	Smit et al. (2019)	3/ 111	MD (95% CI)	No change 13.46 days (-2.46 to 29.38)	Low
Functional status	Physical function (various measures: FIM, Barthel index, 6-minute walk, ADL performance questionnaire)	Smit et al. (2019)	7/ 354	SMD (95% CI)	No change -0.11 (-0.32 to 0.10)	Low
	Physical activity (SDSCA, PASE)	Fredrix et al. (2018)	2/ not clear	Not reported	No change	Very low
	Activity (as defined by the ICF)	Levack et al. (2015)	4/ 223	SMD (95% CI)	No change 0.04 (-0.22 to 0.31)	Low
	Recovery	Sugavanam et al. (2012)	4/ 193	Not reported	↑ in performance and satisfaction score of the COPM & positive result for goal achievement	Low (one study moderate)
	Physical activity (measured by step count)	Bravata et al. (2007)	RCTs (8)/ 155 intervention 122 control group Observational studies (18)/ 2490	MD (95% CI)	For RCTs: 2004 steps/day more in intervention participants than the control participants (878-3129 steps/day, *P*<0.001) For observational studies: 2183 steps/day more than baseline (1571-2796 steps/day, *P*<0.001)	Moderate
General health perception	Self-efficacy	Liao et al. (2019)	2/ 170	Not reported	↑ self-efficacy at each follow-up	Low
	Asthma related-QoL	Liao et al. (2019)	7/ 699	Not reported	↑ in total scores of QoL (continued up to 24 months)	Low
	Self-efficacy	Fredrix et al. (2018)	5/ not clear	Not reported	Positive change in 4 out of 5 studies	Very low
	Diabetes related-QoL	Fredrix et al. (2018)	7/ not clear	Not reported	Higher post-intervention score in 2 out of 7 studies	Low/very low
	Health-related QoL or self-reported emotional status	Levack et al. (2015)	8/ 446	SMD (95% CI)	↑ health-related QoL 0.54 (0.17 to 0.88)	Very low
	Self-efficacy	Levack et al. (2015)	3/ 108	SMD (95% CI)	↑ in task-specific self-efficacy following rehab 1.07 (0.64 to 1.49)	Very low
	Depression	Coulter et al. (2015)	5/599	SMD (95% CI)	↓ in depression score 0.36 (0.52 to 0.20)	Moderate

	Self-efficacy	Coulter et al. (2015)	5/471	SMD (95% CI)	↑in self-efficacy score 0.25 (0.07 to 0.43)	Moderate
	Condition-specific health perception	Coulter et al. (2015)	4/1300	SMD (95% CI)	No change -0.01 (-0.11 to 0.10)	Moderate
	Patients' perceived self-care ability	Sugavanam et al. (2012)	2/ 142	Mean score in one study & MD with Z score in another	- ↑ in perception of self-care ability compared for participants who were supported to identify, clarify, and express goals and develop strategies to achieve goals compared to no support; 127.74 vs. 115.18; F = 33.36, P<0.001) - ↑ in performance (Z = -5.935, P<0.001) and satisfaction score of the COPM (Z = -5.775, P<0.001). Average change for performance was 3.13 and for satisfaction was 3.29	Moderate Low
Overall quality of life	QoL	Smith et al. (2019)	4/ 178	SMD (95% CI)	No change 0.09 (-0.56 to 0.75)	Low

Note: Studies include all types of experimental design as reported in the reviews. Where necessary results of different designs are reported separately.

*Quality of evidence for each outcome is based on review authors' judgment using quality appraisal tool reported in their reviews.

Abbreviations: BMI: Body Mass Index; SMD: Standard Mean Difference; MD: Mean Difference; CI: Confidence Interval; ACQ: Asthma Control Questionnaire; QoL: Quality of Life; ED: Emergency Department; FIM: Functional Independence Measure; ADL: Activities of Daily Living; SDSCA: Summary of Diabetes Self-Care Activities questionnaire; PASE: Physical Activity Scale for Elderly; ICF: International Classification of Functioning; COPM: Canadian Occupational Performance Measure

Table 4 Description of meta-analyses

	#Studies	Total N of participants	Summary random effect size (95% CI)	95% Prediction interval	Random effect p-value	I^2 (%)	Favours goal setting (↑) vs No change (Ø)	Grading
HbA1c*	5	931	-0.22 (-0.40 to -0.04)	-1.25 to 0.81	$P = 0.02$	22	↑	Weak
HbA1c*	9	1916	-.024 (-0.35 to -0.41)	-0.37 to -1.07	$P < 10^{-6}$	64	↑	Suggestive
Cholesterol (mg/dl)	5	1545	0.01 (-0.09 to 0.11)	-1.17 to 1.19	$P = 0.87$	40	↑	Non-significant
Systolic Blood Pressure (mm/Hg)	6	1200	-2.64 (-4.47 to -0.82)	-5.88 to 0.60	$P = 0.004$	67	↑	Suggestive
Body weight*	3	596	0.06 (-1.17 to 1.28)	-7.85 to 7.97	$P = 0.96$	0.00	Ø	Non-significant
BMI* (kg/m^2)	4	822	-0.11 (-0.35 to 0.13)	-0.63 to 0.42	$P = 0.39$	0.00	Ø	Non-significant
Engagement in rehab	9	369	0.30 (-0.07 to 0.66)	-0.82 to 1.42	$P = 0.11$	63	↑	Non-significant
Duration of rehab (days)*	3	111	13.46 (2.46 to 29.38)	-153.11 to 180.03	$P = 0.10$	54	Ø	Non-significant
Physical function	7	354	-0.11 (-0.32 to 0.10)	-0.38 to 0.16	$P = 0.32$	0.00	Ø	Non-significant
Physical activity (step count)*	8	277	2004 step/day (878-3129)	599 to 3408	$P < 0.001$	91	↑	Weak
Activity†	4	223	0.04 (-0.22 to 0.31)	-0.55 to 0.63	$P = 0.75$	0.00	Ø	Non-significant
Self-efficacy†	3	108	1.07 (0.64 to 1.49)	-1.65 to 3.79	$P < 10^{-6}$	0.00	↑	Weak
Self-efficacy	5	471	0.25 (0.07 to 0.43)	0.04 to 0.54	$P = 0.007$	56	↑	Weak
Depression	5	599	-0.36 (-0.52 to -0.20)	-1.27 to 0.55	$P < 10^{-6}$	80	↑	Weak
Condition-specific health perception	4	1330	-0.01 (-0.11 to -0.10)	-0.25 to 0.23	$P = 0.91$	87	Ø	Non-significant
Health-related QoL†	8	446	0.54 (0.17 to 0.88)	-0.53 to 1.61	$P = 0.004$	66	↑	Weak
QoL	4	178	0.09 (-0.56 to 0.75)	-2.96 to 3.14	$P = 0.78$	75	Ø	Non-significant

*effect sizes are based on mean difference (MD). For other outcomes, effect sizes are based on standard mean differences (SMD).

† 3 other meta-analyses had been conducted on these three health outcomes in the same review. These meta-analyses were comparing "structured goal setting" versus "no structure goal setting". Since all other meta-analyses were based on the comparison between "goal setting" versus "no goal setting/usual care", the reports of these three meta-analyses are not included in the table. No change was reported.

Grading: Strong (class I): number of cases>1000, $P<10^{-6}$, $I^2<50\%$, 95% confidence interval excluding null

      Highly suggestive (class II): number of cases>1000, $P<10^{-6}$, largest study with a statistically significant effect and class I criteria not met

      Suggestive (class III): number of case>1000, $P<10^{-3}$ and class I-II criteria not met

      Weak (class IV): $P<0.05$ and class I-III criteria not met

      Non-significant when $P>0.05$

Appendix A MEDLINE (Ovid) search strategy

1. exp HIV/

2. exp HIV Long-Term Survivors/

3. exp HIV infection/

4. HIV*.tw,kf.

5. exp chronic disease/

6. (chronic* or multiple* or morbidity* or multi-morbid*).tw,kf.

7. exp Arthritis/

8. Asthma/

9. exp Pulmonary Disease, Chronic Obstructive/

10. dementia/ or alzheimer disease/

11. exp Diabetes Mellitus/

12. exp Hypertension/

13. exp stroke/

14. exp irritable Bowel Syndrome/

15. exp celiac Disease/

16. exp epilepsy/

17. exp multiple Sclerosis/

18. exp parkinsonian Disorders/

19. osteoporosis/ or osteoporosis, postmenopausal/

20. exp Rehabilitation/

21. exp chronic kidney disease/

22. (arthriti* or asthma* or "chronic obstructive" or copd or diabet* or hypertensi* or stroke or epilep* or "irritable bowel" or IBD or IBS or multiple sclerosis or parkinsons or parkinsonism or osteoporosis or rehabilitat*).tw.

23. or/1-22

24. exp Self Care/

25. exp Self Management/

26. exp Goals/

27. ("self management" or "self care" or self-management or self-care or challenge).tw,kf.

28. (goal adj3 (set or setting or plan or planning or specificity)).tw,kf.

29. or/24-28

30. 23 and 28

31. limit 30 to (english and ("review" or "systematic review"))

Appendix B. Reference list for the excluded reviews

1.   Vermunt N, Harmsen M, Westert GP, Olde Rikkert MGM, Faber MJ. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: A systematic review. *BMC Geriatr*. 2017;17:167

2.   Parke HL, Epiphaniou E, Pearce G, Taylor SJC, Sheikh A, Griffiths CJ, et al. Self-management support interventions for stroke survivors: A systematic meta-review. *PLoS ONE*. 2015;10 (7)

3.   Poulin V, Korner-Bitensky N, Dawson DR, Bherer L. Efficacy of executive function interventions after stroke: A systematic review. *Top Stroke Rehabil*. 2012;19:158-171

4.   Korpershoek C, van der Bijl J, Hafsteinsdóttir TB. Self-efficacy and its influence on recovery of patients with stroke: A systematic review. *J Adv Nurs*. 2011;67:1876-1894

5.   Rae-Grant AD, Turner AP, Sloan A, Miller D, Hunziker J, Haselkorn JK. Self-management in neurological disorders: Systematic review of the literature and potential interventions in multiple sclerosis care. *J Rehabil Res Dev*. 2011;48:1087-1100

6.   Hoffmann T, Bennett S, Koh CL, McKenna KT. Occupational therapy for cognitive impairment in stroke patients. *Cochrane Database Syst Rev*. 2010;2010:Cd006430

7.   Ellis G, Mant J, Langhorne P, Dennis M, Winner S. Stroke liaison workers for stroke patients and carers: An individual patient data meta-analysis. *Cochrane Database Syst Rev*. 2010;2010:Cd005066

8.   Ko H, Turner T, Jones C, Hill C. Patient-held medical records for patients with chronic disease: A systematic review. *Qual Saf Health Care*. 2010;19:e41

9.   Smith J, Forster A, Young J. Cochrane review: Information provision for stroke patients and their caregivers. *Clin Rehabil*. 2009;23:195-206

10.   Aziz NA, Leonardi-Bee J, Phillips M, Gladman JR, Legg L, Walker MF. Therapy-based rehabilitation services for patients living at home more than one year after stroke. *Cochrane Database Syst Rev*. 2008;2008:Cd005952

11.   Legg LA, Lewis SR, Schofield-Robinson OJ, Drummond A, Langhorne P. Occupational therapy for adults with problems in activities of daily living after stroke. *Cochrane Database Syst Rev*. 2017;7:Cd003585

12.   Lui MH, Ross FM, Thompson DR. Supporting family caregivers in stroke care: A review of the evidence for problem solving. *Stroke*. 2005;36:2514-2522

13.   Walker MF, Leonardi-Bee J, Bath P, Langhorne P, Dewey M, Corr S, et al. Individual patient data meta-analysis of randomized controlled trials of community occupational therapy for stroke patients. *Stroke*. 2004;35:2226-2232

14.   Outpatient Service Trialists. Therapy-based rehabilitation services for stroke patients at home. *Cochrane Database Syst Rev*. 2003;2003:Cd002925

15.   Steultjens EM, Dekker J, Bouter LM, van de Nes JC, Cup EH, van den Ende CH. Occupational therapy for stroke patients: A systematic review. *Stroke*. 2003;34:676-687

16. Casimir YE, Williams MM, Liang MY, Pitakmongkolkul S, Slyer JT. The effectiveness of patient-centered self-care education for adults with heart failure on knowledge, self-care behaviors, quality of life, and readmissions: A systematic review. *JBI Database Syst Rev Implement Rep*. 2014;12:188-262

17. Cramp F, Berry J, Gardiner M, Smith F, Stephens D. Health behaviour change interventions for the promotion of physical activity in rheumatoid arthritis: A systematic review. *Musculoskeletal Care*. 2013;11:238-247

18. Eisele A, Schagg D, Kramer LV, Bengel J, Gohner W. Behaviour change techniques applied in interventions to enhance physical activity adherence in patients with chronic musculoskeletal conditions: A systematic review and meta-analysis. *Patient Educ Couns*. 2019;102:25-36

19. Ho TJH, Lee CCS, Wong SN, Lau Y. Internet-based self-monitoring interventions for overweight and obese adolescents: A systematic review and meta-analysis. *Int J Med Inform*. 2018;120:20-30

20. Krasny-Pacini A, Chevignard M, Evans J. Goal management training for rehabilitation of executive functions: A systematic review of effectiveness in patients with acquired brain injury. *Disabil Rehabil*. 2014;36:105-116

21. Soni A, Ng SM. Intensive diabetes management and goal setting are key aspects of improving metabolic control in children and young people with type 1 diabetes mellitus. *World J Diabetes*. 2014;5:877-881

22. Marley J, Tully MA, Porter-Armstrong A, Bunting B, O'Hanlon J, Atkins L, et al. The effectiveness of interventions aimed at increasing physical activity in adults with persistent musculoskeletal pain: A systematic review and meta-analysis. *BMC Musculoskelet Disord*. 2017;18 (1)

23. Levack WMM, Taylor K, Siegert RJ, Dean SG, McPherson KM, Weatherall M. Is goal planning in rehabilitation effective? A systematic review. *Clin Rehabil*. 2006;20:739-755

24. Avery L, Flynn D, Van Wersch A, Sniehotta FF, Trenell MI. A systematic review of behaviour change interventions targeting physical activity, exercise and HbA1c in adults with type 2 diabetes. *Diab Med*. 2012;1):101

25. Burgess E, Hassmen P, Welvaert M, Pumpa KL. Behavioural treatment strategies improve adherence to lifestyle intervention programmes in adults with obesity: A systematic review and meta-analysis. *Clinl Obes*. 2017;7:105-114

26. Casey B, Coote S, Hayes S, Gallagher S. Changing physical activity behavior in people with multiple sclerosis: A systematic review and meta-analysis. *Arch Phys Med Rehabil*. 2018;99:2059-2075

27. Knittle K, Maes S, De Gucht V. Psychological interventions for rheumatoid arthritis: Examining the role of self-regulation with a systematic review and meta-analysis of randomized controlled trials. *Arthritis Care Res*. 2010;62:1460-1472

28. Lo S, Chang AM, Chau JPC, Gardner G. Theory-based self-management programs for promoting recovery in community-dwelling stroke survivors: A systematic review. *JBI Database Syst Rev Implement Rep*. 2013;11:157-215

29.   Sangelaji B, Smith CM, Paul L, Sampath KK, Treharne GJ, Hale LA. The effectiveness of behaviour change interventions to increase physical activity participation in people with multiple sclerosis: A systematic review and meta-analysis. *Clin Rehabil.* 2016;30:559-576

30.   van Erp RMA, Huijnen IPJ, Jakobs MLG, Kleijnen J, Smeets RJEM. Effectiveness of primary care interventions using a biopsychosocial approach in chronic low back pain: A systematic review. *Pain Pract.* 2019;19:224-241

31.   Willett M, Duda J, Fenton S, Gautrey C, Greig C, Rushton A. Effectiveness of behaviour change techniques in physiotherapy interventions to promote physical activity adherence in lower limb osteoarthritis patients: A systematic review. *PLoS ONE.* 2019;14 (7)

32.   Yun D, Choi J. Person-centered rehabilitation care and outcomes: A systematic literature review. *Int J Nurs.* 2019;93:74-83

33.   Hecke AV, Heinen MM, Fernandez-Ortega P, Graue M, Hendriks JM, Hoy B, et al. Systematic literature review on effectiveness of self-management support interventions in patients with chronic conditions and low socio-economic status. *J Adv Nurs.* 2017;73:775-793

34.   Parry M, Bjornnes AK, Victor JC, Ayala AP, Lenton E, Clarke H, et al. Self-management interventions for women with cardiac pain: A systematic review and meta-analysis. *Can J Cardiol.* 2018;34:458-467

35.   Warner G, Packer T, Villeneuve M, Audulv A, Versnel J. A systematic review of the effectiveness of stroke self-management programs for improving function and participation outcomes: Self-management programs for stroke survivors. *Disabil Rehabil.* 2015;37:2141-2163

36.   Lepard MG, Joseph AL, Agne AA, Cherrington AL. Diabetes self-management interventions for adults with type 2 diabetes living in rural areas: A systematic literature review. *Curr Diab Rep.* 2015;15

37.   Peek K, Sanson-Fisher R, Mackenzie L, Carey M. Interventions to aid patient adherence to physiotherapist prescribed self-management strategies: A systematic review. *Physiotherapy.* 2016;102:127-135

38.   Villa-Roel C, Voaklander B, Ospina MB, Nikel T, Campbell S, Rowe BH. Effectiveness of written action plans for acute asthma: A systematic review. *J Asthma.* 2018;55(2):188-195.

39.   Lenferink A, Brusse-Keizer M, van der Valk PD, et al. Self-management interventions including action plans for exacerbations versus usual care in patients with chronic obstructive pulmonary disease. *Cochrane Database Syst Rev.* 2017;8(8):Cd011682.

40.   Gatheral TL, Rushton A, Evans DJW, et al. Personalised asthma action plans for adults with asthma. *Cochrane Database Syst Rev.* 2017(4).

Appendix C

Supplementary Table 1 Characteristics of included systematics reviews

Author (year)	Objectives (as reported in the reviews)	Meta-analysis	Total number/ study design/ country of origin	Chronic condition	Intervention delivery settings	No. of database searched (Date range of search)	Date range of included studies	Instrument of quality appraisal tool
Bravata et al. (2007)	1) To evaluate the association of pedometer use with physical activity and health outcomes among outpatient adults. 2) to determine the association between pedometer use and changes in body weight, serum lipid levels, fasting serum glucose and insulin, and blood pressure. 3) to evaluate the association between setting a daily step goal and improvements in health outcomes.	Yes	26 RCT (8), observational studies with before-after or cohort design (18) USA or Canada (20), Japan (2), Europe (2), Australia (2)	Outpatient adults with different conditions including diabetes, COPD, sedentary, MI completing cardiac rehab, HTN, arthritis, healthy adults, women >60 with BMI >30, Neuromuscular disease	Adult outpatients enrolled in physical activity programs	7 (1966 - 2007)	2001- 2006	Consensus based appraisal items
Sugavanam et al. (2013)	1. To investigate the effects of goal setting in stroke rehabilitation on physical function and psychological function. 2. To explore the experiences of people affected by stroke and their treating professionals in relation to goal setting	No	7 Non-RCT (2), before-after study (2), cohort (3), Australia (2), US (2), Canada (1), UK (1), Sweden (1)	Stroke	No information	13 (From their inception to April 2011)	1993-2010	Effective Public Health Practice Project (EPHPP) instrument for quantitative studies, McMaster University Occupational Therapy Evidence-Based Practice Research Group for qualitative studies
Levack et al. (2015)	1. To assess the effects of goal setting, and strategies to enhance goal pursuit, on health outcomes in adults with acquired disability participating in rehabilitation	Yes	39 RCT (27), cluster-RCT (6), non-RCT (6) Hong Kong (1), Sweden (2), New Zealand (6), USA (17), Canada (3), UK (7), Swiss (1), Denmark (1), Netherlands (1)	Acquired disability participating in rehabilitation (conditions included stroke, musculoskeletal or chronic pain, mental health conditions, cardiovascular, age-related disability, diabetes mellitus, and respiratory disorder)	Primary care, residential and outpatient-based rehabilitation, community and/or residential care, short term residential rehabilitation unit for chronic pain	10 (From their inception to December 2013)	1971 - 2013	Cochrane Handbook for Systematic Reviews of Interventions

Coulter et al. (2015)	1. To assess the effects of personalised care planning for adults with long-term health conditions compared to usual care (i.e., forms of care in which the active involvement of patients in treatment and management decisions is not explicitly attempted or achieved)	Yes	19 RCT (16),cluster RCT(3) USA (13), Australia, China, Denmark, Netherland, Taiwan, UK (one each)	Diabetes Mellitus, Mental health, Heart failure, renal disease, asthma	Hospital clinics, primary care, community centre	7 (From their inception to July 2013)	1978 - 2013	Cochrane Handbook for Systematic Reviews of Interventions
Fredrix et al. (2018)	1. To assess the effectiveness of goal setting behavioural change interventions on clinical, health, psychosocial or behavioural outcomes in people with diabetes. 2. To identify which "Goals and planning" and "Feedback and monitoring" BCTs are most frequently used in these interventions and which are most effective in improving outcomes.	Yes	14 RCT (8) , before-after study (4) USA (11), UK (1), NL (2)	Diabetes Mellitus type 1 and 2	Medical and community health center, Patients' home	5 (From their inception to January 2016)	1996 - 2013	Cochrane Risk of Bias Tool
Liao et al. (2019)	1. To investigate the effectiveness of goal setting technique incorporating with asthma self-management education on the outcomes in asthma morbidity, quality of life and healthcare use	No	6* RCT (3), cluster RCT (3) USA (2); Australia (2), UK (1), Switzerland (1)	Asthma	No information	5 (From their inception to February 2019)	2007 - 2017	JBI critical appraisal checklist for RCTs
Smit et al. (2019)	1. To investigate the effects of goal setting in geriatric rehabilitation	Yes	14 RCT (7), cluster RCT (2) and non-RCT (4), before-after study (1) Country not reported	Older adults with acquired disabilities	Inpatient, outpatient, and combined rehabilitation setting	5 (From their inception to October 2018)	2000 - 2016	Cochrane Risk of Bias Tool

*This review had 9 studies included of which 3 were on children and did not meet the criteria of our umbrella review. Hence, those have been deleted and the report here is based on the total of 6 studies. Two of 6 RCT studies were pilot studies and one used mixed methods that had both qualitative and quantitative results.

Appendix D

Supplementary Table 2 Description of the interventions and delivery methods reported in the included reviews

Author (year)	Intervention details	Delivery method	Comparison	Primary outcome	Secondary outcome	Follow-up time
Bravata et al. (2007)	Varied among studies: Use of pedometer, use of physical activity and physical activity counseling, Dietary counseling (only in 3 studies), log for step count, workplace activity, individualized goal or step goals were mainly included (22)	Group-based and individual format	Reduced exposure/ normal counseling compared to intervention group/ pre-intervention data for observational studies	Physical activity measured by step count	BMI, BP, Lipid profile, fasting glucose	3 weeks to 26 months (mean of 18 weeks)
Sugavanam et al. (2012)	Studies involved any form of goal setting (e.g., COPM, GAS) and evaluated either the effects and/or experiences of goal setting	Different perspectives have been used (e.g., client-centered practice, cognitive rehabilitation and goal attainment)	Only one study had a control group which no information was provided N/A for other studies	Recovery, patients' perceived self-care ability, engagement in rehabilitation	N/A	Reported only in one study (no information for other included studies)
Levack et al. (2015)	Varied among studies from employing named approaches (e.g., GAS, COPM, ICFC) to theory-based approaches (e.g., King's nursing theory of goal attainment, Locke and Latham's model) Participants were actively involved in 31 studies in the process of goal selection, the process was mainly collaborative in all but 3 studies where a predefined list of goals was used. Two studies involved family members in the process of goal setting	Group-based (2), Family-centered approach (1), individual + group-based rehabilitation classes (1), Individual format (34)	No goal setting, "usual care" that may involve some goal setting but where no structured approach was followed or no interventions to enhance goal pursuit	Health-related quality of life or self-reported emotional status; Participation outcomes as defined by the ICF, e.g., work, community integration, social relationships; Activity outcomes as defined by the ICF, e.g., activities of daily living, mobility	Body structure and function as defined by the ICF; Patient self-belief and engagement in rehabilitation, e.g., adherence, patient motivation, self-efficacy; Individual goal attainment; Evaluation of care, e.g., satisfaction with care; Service delivery level, e.g., cost of care, length of stay; Adverse outcomes, e.g., complications, morbidity, mortality, readmission rate.	Ranged from a median of 3 weeks to 6 months

Coulter et al. 2015	Collaborative care planning intervention focused on changing patients' capabilities and behaviour. Tools used were information packages, prompts for patients (e.g., worksheet or decision aids); structure consultations (e.g., motivational interviewing, training, peer support)	either face-to-face or through phone support	Usual care	Physical health (HbA1c, BP, BMI); psychological health; perceived health-related quality of life	self-management capability (e.g., self-efficacy, knowledge); habit behaviours (exercise, diet, medication adherence, self-care activities)	Ranged from 1 to 12 months with a median of 6 months
Fredrix et al. (2018)	Ranged from one single educational goal-setting session to 14 contact moments in the form of phone-based goal-setting sessions (average contact moments 4)	In-person (5), completely phone-based (1), mixed modes of delivery (8)	Usual care	HbA1c, body weight	Self-efficacy, QoL, physical activity, self-monitoring of blood glucose	Not clear for all included studies, varied between 2 weeks to 6 months
Liao et al. (2019)	All studies but one used goal setting as a major component of their intervention, incorporating behavior theory and other problem-solving skills, such as problem identification, personal resource activation, action planning, process evaluation and reward. No study used goal setting as a stand-alone intervention.	In person visit (3), group-based training (1), telephone-based (1), and group counseling combined with telephone follow-up (1).	Usual care or enhanced usual care	Clinical outcome: Asthma control (either with questionnaires or pulmonary function test or asthma severity assessment); Psychosocial outcome: Self-efficacy, asthma quality of life Healthcare utilization outcome: Emergency department visit, hospitalization, unscheduled visit	N/A	6 weeks to 9 months
Smit et al. (2019)	Interventions were based on two approaches: 1) using standard goal setting instruments (8) (e.g., COPM, GAS, ADOC and 2) using standardized approach for goal setting (6) with predefined intervention (e.g., CCSCI, CADL and TCS.	No information (implies as individual sessions)	Usual care	Physical function	QoL, duration of rehabilitation	Not clear,

Abbreviations: GAS: Goal Attainment Scale; COPM: Canadian Occupational Performance Measure; RAP: Rehabilitation Activities Profile; ADOC: Aid for Decision-making in Occupation Choice; ICFC: International Classification of Functioning Cycle; CCSCI: Client-Centered Self Care Intervention; CADL: Client-centered Activities of Daily Living; TCS: Take Charge Session; QoL: Quality of Life; N/A: Not Applicable.

CHAPTER 4: Integration of Manuscripts I & II

Research Objective of Manuscript I

1- To identify, based on the published literature, the components of goal setting interventions and contexts in which they have been used or integrated into chronic disease management.

2- To estimate the magnitude of effect caused by goal setting on improvement of health outcomes.

Research Objectives of Manuscript II

1- To develop a personalized health outcome profile as a feedback tool to improve self-management in people living with chronic conditions such as HIV.

2- To evaluate the interpretability and usefulness of the feedback tool for setting specific goals.

Integration of Manuscript I and II

One of the main objectives of this thesis is to evaluate patients' goal setting capability – a fundamental skill for patient self-management – at the population level.

The first manuscript presented a comprehensive review of the literature on the effect of goal setting for improvement of health outcomes – these studies were of clinical populations. Based on the evidence available from the meta-analyses, it was concluded that goal setting has some small, effect on health outcomes of chronic conditions. As most goals were defined as outcome goals (also known as mastery goals), patients' accomplishments rather than process or performance were measured. Action planning and feedback on behaviour were noticed as the two most commonly used goal setting components. While a collaborative approach was mainly present, a very small proportion of the goals were self-driven – defined by patients alone. Information on goal documentation and patient involvement were largely missing. Thereby, the

evidence does not inform the amount of goal exchange. Whether or not patients are prepared for setting self-management goals for their real-world condition remains unclear.

For many patients, many aspects of the chronic condition can be managed by patient self-management. Therefore, it would be valuable to understand the extent to which they are ready to define their self-management goals. Studies with longitudinal data on multiple domains of quality of life are ideal to provide patients with meaningful information on their adjustment to the chronic condition. The Positive Brain Health Now study (+BHN) with an outcome platform comprised of 20 different questionnaires on health aspects of quality of life for people living with HIV, including one performance test of cognition and information on lifestyle behaviours, allows for the provision of meaningful information to the patients in the form of a feedback tool. The subsequent manuscript in this thesis documents the development and usability testing of a feedback tool – "My Personal Brain Health Dashboard" – for people living with chronic HIV.

CHAPTER 5 : Manuscript II

Development and Usability of a Feedback Tool, "My Personal Brain Health Dashboard",

to Improve Setting of Self-Management Goals Among People Living with HIV in

Canada

Maryam Mozafarinia*[1,7], Fateme Rajabiyazdi[2,3], Marie-Josee Brouillette[4,7], Lesley K. Fellows[5],

and Nancy E. Mayo[1,6,7]

[1]Division of Experimental Medicine, McGill University, [2]Department of Surgery, [3]Steinberg

Bernstein Centre for Minimally Invasive Surgery and Innovation, [4]Department of Psychiatry,

[5]Department of Neurology and Neurosurgery and Chronic Viral Illness service, [6]Department of

Medicine and School of Physical and Occupational Therapy,

[7]Center for Outcome research & Evaluation,

McGill University, Montreal, Canada

Correspondence author:

Maryam Mozafarinia, RN, BScN, MScN,
Division of Experimental Medicine, Faculty of Medicine, McGill University &
Center for Outcome Research and Evaluation (CORE)
McGill University Health Centre Research Institute
5252 de Maisonneuve, Office 2C:13
Montréal, Québec, H4A 3S5
E-mail: maryam.mozafarinia@mail.mcgill

Abstract

Objective: 1) Develop a personalized health outcome profile as a feedback tool to improve self-management in people living with chronic conditions such as HIV and 2) Evaluate the interpretability and usefulness of the feedback tool for setting specific goals.

Methods: The development of "My Personal Brain Health Dashboard" was inspired by the Knowledge-to-Action framework. A health outcome profile was computer generated in SAS from the outcome measures, at first and last recorded visits, of each person enrolled in the +BHN cohort from 5 sites in Canada. The Wilson-Cleary model framed the outcome measurement strategy. Single actionable items with evidence of life impact were chosen. The response option from the original item was the person's value and the optimal level was provided to help persons compare their results to an optimal target. Cognitive interviews were conducted with members of HIV community. Appropriateness of the Dashboard for goal setting was tested by asking participants to write specific goals according to the Dashboard they were given.

Results: 15 respondents were recruited from Montreal and Vancouver. Items most endorsed to be changed were cognition, pain, and body mass index. 80% found the Dashboard useful for setting health-related goals. A total of 85 goals were set, the text of which was mined to create a lexicon for scoring goal quality in future endeavours.

Conclusion: This study was the preparatory phase for a future trial on a method to stimulate setting specific goals. The future trial would provide a thorough understanding of the quality of person-defined goals.

Keywords: Goal-setting, Chronic conditions, HIV/AIDS, Health outcome profile, Cognitive interviews

Introduction

Approximately 38 million people around the globe are living with HIV [1]. With the availability of highly-active antiretroviral therapy in the last two decades, the life span of people living with HIV in many developed countries, including Canada and the United States, is almost the same as the general population [2-4]. Nonetheless, there are concerns about the unique issues adult living with HIV are facing as they age [5] such as higher risk for developing other chronic diseases [6]. It is estimated that in the next decade more than 75% of HIV infected adults will be over the age of 50 with at least one age-related disease. HIV infection is now considered to be a chronic condition[7] and most suitably managed following a chronic care model with the health care team and the individuals living with HIV sharing responsibilities [8,6].

People living with HIV have similar experiences and biopsychosocial determinants of quality of life as any other chronic condition, yet grapple with "stigma and disclosure, and criminalization of HIV exposure" [9,10]. There is emerging support for the benefits of including self-management strategies to improve outcomes of chronic health conditions [11,12]. The cornerstones of self-management are assessment, goal setting, action plans and reassessment. Any successful program needs a mechanism to deliver meaningful and relevant information to patients to help them set goals and make choices that lead to improved health outcomes over time [13]. Goal setting encourages individual accountability, fosters self-efficacy through development of active coping strategies, and allows some control over the health condition with minimum or no supervision [13].

In practice, goals are mostly set in collaboration with a clinician and focus on medical management of the health condition which do not always include biopsychosocial aspects of health. This approach can prevent initiation of self-management discussion [14]. Collaborative

goals are defined as goals set with patients actively engaged in through discussing goals, setting plans and evaluating their condition afterwards [15]. The literature on patients' experience with goal-setting suggests that patients' involvement is often influenced by a mismatch between patients' and practitioners' priorities and attitudes [16-18]. Yet, the concern raised by clinicians with regards to shared goal setting is their perception that patients are unable to make decisions and set *SMART* goals [19] - equated with being specific, measurable, action-planned, realistic, and time-bound [20]. Patients' inability, however, might be partly due to lack of availability of relevant information. If patients do not realize there are aspects of their life that are suboptimal and amenable to intervention, they cannot set goals for targeting these areas.

Data from research projects on health outcomes using performance, self-report, and patient-reported outcomes (PerfO, SRO, PROs) [21] are a rich source of information. While this type of observational approach has scientific value, there is a missed opportunity if the results of the assessments are not communicated back to the participants. They are in the best position to benefit from the information. However, there is no simple way of communicating results back to participants because interpreting this information at the individual level is an important step [22]. Just because people who participate in research filled out a questionnaire, it does not necessarily mean that the process of completing it triggered any identification or reflection on the importance of the answers or actions required to improve the area queried. Informing people about their health profile by providing them with specific and meaningful feedback on actionable health outcomes is one possible strategy to stimulate the reflection, identification, and formulation of specific goals.

This paper presents the preparatory phase for a randomized controlled trial on a method to stimulate setting "*SMART*" goals in people living with HIV in Canada. The specific aims of this

work were 1) to develop a personalized health outcome profile as a feedback tool to improve

self-management in people living with chronic conditions such as HIV and 2) to evaluate the

interpretability and usefulness of the feedback tool for setting specific goals. For clarity, these

two objectives are presented as study 1 and study 2. Methods and results for each study have

been presented separately followed by a general discussion on the overall results. This is an

exploratory study and the data source for this paper was the Positive Brain Health Now (+BHN)

cohort (details of the +BHN has been provided in study 1).

Study 1. Development of "<u>My Personal Brain Health Dashboard</u>"

Theoretical underpinning

The process of developing the "My Personal Brain Health Dashboard" was inspired by the

Knowledge-to-Action framework (KTA) for generating usable knowledge. The objective of the

KTA framework is to guide the process to best generate and implement effective, meaningful,

relevant, practical, and context-specific knowledge transfer to the target end user. For this

application, the KTA framework was adapted to individual end users rather than for health

professionals, or policy makers. The framework comprises two cycles, one for knowledge

creation and one for putting the knowledge into action (Figure 2) [23]. As applied here, the

knowledge inquiry element in this case is not the corpus of scientific literature but rather the

responses of individuals to the items on the +BHN platform. Knowledge synthesis here is not a

systematic review but rather a systematic selection of meaningful and actionable items grouped

on a Profile. The knowledge tool is not a guideline but a visual display of the persons' responses

on the selected items. We have termed this display "My Personal Brain Health Dashboard". The

action cycle component investigated here was identifying problems with the first version of the

Dashboard followed by an assessment of barriers to its use.

Methods

Context for the Study: Positive Brain Health Now Cohort (+BHN)

The +BHN cohort is an ongoing multi-site Cohort Multiple Randomized Controlled Trial

(cmRCT) across five sites in Canada with the core objective of identifying, understanding, and

optimizing brain health in people living with HIV. This design is used to test multiple

interventions within a fully characterized cohort.

The first phase of the +BHN study was conducted over the course of 5 years from 2013 to 2018,

recruiting and evaluating more than 800 HIV positive men and women. Further details of this

study have been published elsewhere [24-26]. All participants were scheduled for four

assessments at 9-month intervals. The outcome measurement strategy was informed by the

Wilson-Cleary model [27] (Figure. 1), a biopsychosocial model integrating multiple components

of health-related quality of life. A unique feature of the +BHN cohort is the emphasis on brain

health conceived as a multi-dimensional construct reflecting the brain's role in cognition, mood,

motivation and vitality. Within the Wilson-Cleary model, the brain health outcomes are situated

under the symptom rubric. Cognition was evaluated by both performance and self-report

outcomes (PerfO; SRO); other brain health outcomes were evaluated with patient-reported

outcomes (PROs). The other components of the Wilson-Cleary model, downstream from the

brain health outcomes (symptom rubric), were evaluated with SROs or PROs. As reported

previously [26], the +BHN outcome platform comprised 20 different SROs or PROs, one PerfO,

as well as questions about age, sex, education, drug and alcohol consumption, smoking, and nutrition.

To optimize the interpretability of providing information to participants on their outcomes, we first chose to develop a visual display and then test it for acceptability to the intended participants and usability for goal setting.

Item selection

The objective was to create a feedback tool to deliver meaningful and relevant information to participants about their health status; to improve their ability to reflect on their own health status, set goals and make choices that would eventually lead to improved health outcomes. Items included on the Dashboard are selected from the +BHN platform outcomes. Single actionable items with evidence of life impact [26,28] were chosen to cover cognition, pain, fatigue, motivation, and worrisome thoughts (impairments/symptoms), physical and cognitive capacities (function), health perception, quality of life, and lifestyle (personal) factors. All items have sufficient psychometric strength warranting their use as an alternative to multi-item questionnaires [29]. Since the goal was to empower participants to take charge of managing their own health situation, only actionable items that might influence overall quality of life were selected. Non-actionable items reflecting the biological and physiological component of their health condition were avoided. Table 1 provides examples of actionable versus non-actionable items.

Selection of the items was through the collective agreement of the multidisciplinary team of +BHN investigators with expertise in psychiatry, neurology, epidemiology, and health outcomes research. Initially, 14 items were selected. However, further discussion led to removal of waist circumference as lipohypertrophy in some body areas, most commonly abdomen, can be a side

73

effect of certain anti-retroviral medications [30] and life-style changes such as diet and exercise usually do not significantly change abdominal fat in this context [31]. Smoking and feeling lonely were not initially among the 14 selected items but were added later.

Table 2 shows Dashboard items, the source for each item, and corresponding response options for each item as used in the original questionnaire. Lay language was used to present each item.

Creation of the Dashboard

A Dashboard was computer generated from the selected Profile items, based on the data from the first and last recorded visits, of each person enrolled in the +BHN cohort. This Dashboard was generated using the PROC REPORT procedure using Statistical Analysis System (SAS) Version 9.4. The variables were positioned in the data set in the order so that values from the first visit were presented first, followed by values from the most recent visit.

The response option from the original item (selected by the participant) was the person's value, and an optimal (target) level was provided to help persons interpret their own response. These optimal levels were obtained from the response options of the original questions. Persons' results were color coded in either green or beige, where green indicated that the person is at the optimal level. A brief description was provided at the bottom of the Dashboard to show the number of items the person had within the optimal range at each timepoint, for each person. Figure 3 shows the first version of the Dashboard. SAS codes for creation of the Dashboard is provided in the online supplementary material [32].

Cognitive debriefing

Using cognitive debriefing, participants were interviewed by two experienced interviewers following an interview guide. Data collection was an iterative process, i.e. comments and

concerns of two to three participants were used to modify the Dashboard for the next respondents. Verbal cues were used to probe each item on the Dashboard for clarity and meaning. The interpretation and clarity of the titles, results, and optimal levels were also probed. Participants were also asked to comment on the design, color, and general layout of the Dashboard.

Responses were summarized and compared across respondents for each item on the profile, with particular attention to similarities, differences, and frequencies of the types of comments. Changes were made after discussion with the +BHN investigators. In response to some comments, text was added to the Dashboard to aid interpretation.

Participants

A convenience sample of 15 HIV+ adults was recruited from Montreal and Vancouver. This sample size was sufficient, as data showed saturation - the point where no new issues arose with interpretability and feasibility of the use of the dashboard. English and French versions of the Dashboard were tested simultaneously. 73% of participants were men. One participant was unilingual French-speaking, 4 were bilingual, French and English, and the rest were English-speaking. Thus, the French version of the Dashboard was reviewed by 5 participants and the English version by 11. Comments for both versions were similar. Therefore, the results are presented across all participants.

Results

Feedback on the items of the Dashboard

Items that were difficult to interpret were cognition, pain, body mass index (BMI), and smoking. and the Dashboard was modified to improve interpretation.

Cognitive test score (B-CAM score) [33-36]: 40% of participants had difficulty understanding "cognitive test score". Participants often asked for clarification; some also linked it to the IQ score. It was also suggested that the results be presented in numeric format instead of the narrative. One participant asked what the comparison for this item was, meaning whether the results of the participants who took this test were compared to a standardized norm. Providing background information as to what the cognitive test was in the original study made it easier for participants to understand the item. It appeared that the label "cognitive test score" alone would not be enough to help the reader to understand that this item is the result of a performance test showing cognitive ability.

Participants' feedback was shared with the research team. As simply providing the individual's score would not help the interpretability of this item, it was rather decided to consider extra explanation to remind participants of the computer tests they took during their participation in the +BHN study.

Pain: 40% of participants expressed difficulty comprehending a person's value related to pain. Participants' comments on this item were mainly about having more precision on how pain was queried. For example, "do the values on the Dashboard reflect chronic or an acute pain?" It was also mentioned that because pain severity changes, it is hard to relate to the reported value without knowing how or when it was measured.

As presented earlier in Table 2, at each visit +BHN participants were asked to report on the bodily pain they had experienced in the last 4 weeks. Based on these comments, "pain" was re-worded as "your pain rating". A brief instruction at the beginning of the Dashboard as a guide on how to read the Profile was also added.

BMI: 13% of participants asked for more clarification as to what BMI is and how it affects their health. This item thus was re-worded as weight to height ratio.

Smoking: Comments on this item was with regards to person values and target level. This item was based on the question: Are you a current smoker?" with a binary response option, "yes" or "no". Participants found it confusing to see values as yes or no. We noted that participants were interpreting "yes" as a positive answer and were expecting to see it coded in green. To avoid this confusion, person values were reworded to "smoking" and "not smoking".

Feedback on color and general layout

Even though the use of color was appreciated by participants, the two-colour choice was criticized, as it was interpreted as dichotomous, either good or bad. There was also a comment about those items where the target value was "excellent". One participant commented "*what if good is enough for me?*" meaning that even though he or she was not excellent, it might be good enough.

Most participants suggested the use of traffic light colors as a way of presenting person values with the exception of using orange instead of red as the color red has been predominantly used as a warning sign. A few participants also commented on the use of more vivid colors. In response to these comments, person values for the items were redefined in three categories. Applying the concept of the traffic light, three colors were used: green if the values met the target level; beige where values were below the target level but not too far away; and orange where the values were further away from the target level.

Also, during the interviews it was noted that items with no response were automatically coded as below the target and therefore were colored beige; this issue was fixed with recoding in SAS, so they appear in white instead.

80% of participants mentioned that the Dashboard held their attention. Below are examples of participants' comments:

"*Easy format, not too cluttered*"
"*It is organized as a report card*"
"*Color coding is nice*"

However, there were some overall comments:

"*Easy to follow if somewhat discouraging*"
"*I can follow it like a report card but need context or someone to help me*"
"*Good indicators, it's helpful*"

Comments suggested that a short description at the beginning of the Dashboard was necessary to walk the reader through the Dashboard so they could interpret the results. No new issues arose within the last 4 interviews. Table 3 is a saturation grid listing major difficulties noticed during cognitive debriefing. Figure 4 shows the final version of the Dashboard. Reflecting on participants' comments, the research team decided to reword the heading terms. "Target" reworded as "optimal" and "Profile" reworded as "important brain health areas" to avoid terms that sound clinical and to minimize the effort required to understand the information presented.

Study 2. Testing the usability of the Dashboard for setting specific goals

Methods

The ultimate use of the Dashboard was for goal-setting. To test the usability of the Dashboard for setting specific goals, two sets of data were tapped. The first source was through the cognitive

debriefing on the Dashboard, described above. At the beginning of the cognitive interviews, participants (n=10) were asked to write 3 to 5 goals on any area of health they would like to work on to improve their health – these goals we termed "uninformed goals". At the end of the cognitive interviews, participants were queried as to whether or not the Dashboard seemed helpful for setting health-related goals. Again, participants were asked to write 3 to 5 goals but this time according to the sample of the Dashboard they were given. To make it easier for participants, they were told to think of the Dashboard as their own result and choose areas which they would want to improve. These goals were termed "informed goals". For both sets of goals participants were given a pamphlet containing instructions on goal-setting. Both sets of person-defined goals were collected at the end of the interview session. The second source of data, used as a point of comparison, was a set of goals set collaboratively between the participants (n=10) and a clinician during another project on health outcomes post-hospitalization [37] – these were termed "supervised goals".

Application of text mining

Clinically, goals are set collaboratively between the patient and a clinician because without clinical input, goals are commonly poor in quality and not *SMART*; thus, will not produce the desired effect on health outcomes. However, for application at a population level, clinicians are not readily available for goal coaching. Measuring goal quality is an important intermediate step in the goal-outcome continuum. However, unsupervised person-defined goals lack the structure and format of *SMART* goals elaborated clinically. Text mining offers a way of organizing free text into pre-defined groupings that can be analyzed to identify patterns in goal-setting quality. The main outcome of the text mining process here was the count of the number of *SMART* elements by identifying specific words and actionable verbs. A measurement framework and an

79

initial lexicon (collection of vocabularies) were developed for the goal evaluation [32]. Using text mining techniques (i.e., tokenizing and *pos*-tagging), the specific components of each goal were extracted and compared to the lexicon using regular expression algorithms. Python programming language and software libraries such as *panda* [38]– an open source software library written for the Python programming language for data structure and analysis – and natural language toolkit (*nltk*) [39] were used for data manipulation and analysis. Further details is available in the online supplementary material [32].

Results

Supervised goals had the most specific words whereas uninformed goals had the fewest. Supervised goals also had more actionable verbs than informed goals, while uninformed goals mainly used neutral verbs. Details of the quality of the goals among the three groups are shown in Table 3. The informed group mainly used items of the Dashboard and set their goals according to the areas that were below the optimal levels. Uninformed goals on the other hand used more general words. Word visualization for informed and uninformed groups is shown in Figure 5.

Discussion

In this cognitive debriefing study, we pretested the Dashboard designed for +BHN participants to capture issues threatening interpretation and applicability of the content. Participant feedback was used to reframe the Dashboard and add an introduction to orient users as what data was used to populate the Dashboard, what was presented, and also to remind them that the results might not necessarily represent their current health situation (i.e. given that these data were collected previously, within the +BHN study). Last version of the Dashboard can be seen in Figure 4.

80

Overall, we found that the changes required to improve readability and comprehensiveness of the Dashboard were modest.

Evidence in various chronic conditions and specifically in HIV show improvement of physical (e.g., symptom severity) and psychosocial (e.g., self-efficacy, depression) outcomes with self-management strategies [40-42]. According to Swendeman and colleagues [9], most HIV self-management interventions are limited to only a short period of time, and lack reports on patient engagement level. Even though some interventions were goal oriented, it is not clear whether or not a goal-setting component was included. Nonetheless, maintenance of health outcomes beyond 3 months is yet to be studied. Studies with longitudinal data on multiple domains of quality of life, like the +BHN, could provide a better picture of patients' adjustment with their chronic condition. Our developed Dashboard focuses on items that are common among chronic conditions but are of higher importance for HIV+ adults as they are also more at risk of multimorbidity. The novelty of the Dashboard is that it does not over-emphasis on any specific area, rather with color coding it flags importance of a behaviour change for certain areas and leaves it to the individuals to prioritize. The Dashboard is a self-assessment tool which aims to stimulate individuals to become a responsible self-manager.

Text mining has been used in several health datasets and has been shown to be an effective tool for extraction of critical information [43]. To our knowledge, text mining has not been used on person-defined textual data within healthcare research studies. Our testing process for the usability of the Dashboard to set specific goals suggests that this approach shows promise.

Using text mining techniques, the contents of person-defined goals can be quantified. This method has additional benefits in terms of building a comprehensive goal-related lexicon that could be used for other goal applications. With more data, clustering techniques can be applied

to shed light on the preoccupations of people with chronic conditions with respect to health outcomes. While the sample here was people with HIV, there is no reason why this model could not be applied to people with other chronic conditions.

There are some limitations with regards to the results presented on the Dashboard. Dashboard items have been selected by the research team only. Due to large number of items on the +BHN platform, the research team decided to perform their due diligence before handing the Dashboard to participants. Feedback on the developed Dashboard was sought afterwards and changes made on the Dashboard are based on participants' comments. However, it is possible that the focus of the Dashboard is not exactly aligned with participants' priorities. The results are based on PerfO, PROs, and SROs which are performance of individuals at the time of the study and their self-reports based on how they evaluated themselves at the time responding to the questionnaires. These outcomes are self-perspectives and can change over time. However, this limitation is embedded in any research study. Also, the color-code feature of the Dashboard might be interpreted differently by persons with some visual disabilities (e.g., color blindness). Though colors are explained, this might minimize visual attraction of the Dashboard. Despite these limitations, the Dashboard highlights common areas affecting a person's quality of life which are amenable to change. Participants can use items to evaluate their current health status and see whether or not they meet the optimal level. Our next step is to test the effectiveness of the Dashboard on setting specific self-management goals with a larger population.

Data availability

Online supplementary data is available in Open Science Framework: Development and Usability of a Feedback Tool, "My Personal Brain Health Dashboard", to Improve Setting of Self-Management Goals Among People Living with HIV in Canada, http://doi.org/10.17605/OSF.IO/3GZCX [32]

This project contains the following online supplementary data:

- Goal evaluation guideline for text mining

- Text mining steps

- Initial start-up lexicon (English & French)

- SAS codes for creation of the Dashboard

References:

1. World Health Organization (2018). Global Health Observatory (GHO) data - Summary of the global HIV epidemic (2018). https://www.who.int/gho/hiv/en/. Accessed Jan 17 2020.

2. Samji, H., Cescon, A., Hogg, R. S., Modur, S. P., Althoff, K. N., Buchacz, K., et al. (2013). Closing the gap: Increases in life expectancy among treated HIV-positive Individuals in the United States and Canada. *PLoS ONE [Electronic Resource], 8*(12), e81355, doi:https://doi.org/10.1371/journal.pone.0081355.

3. Katz, I. T., & Maughan-Brown, B. (2017). Improved life expectancy of people living with HIV: Who is left behind? *The Lancet HIV, 4*(8), PE324-E326, doi:https://doi.org/10.1016/S2352-3018(17)30086-3.

4. World Health Organization (2017). HIV: From a devastating epidemic to a manageable chronic disease. In *Ten years in public health, 2007–2017: Report by Dr Margaret Chan, Director-General, World Health Organization*. Geneva: World Health Organization, Licence: CC BY-NC-SA 3.0 IGO.

5. Hawkins, K. L., Brown, T. T., Margolick, J. B., & Erlandson, K. M. (2017). Geriatric syndromes: New frontiers in HIV and sarcopenia. *Aids, 31*(Suppl 2), S137-S146.

6. Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *Lancet (London, England), 382*(9903), 1525–1533, doi:10.1016/S0140-6736(13)61809-7.

7. Public Health Agency of Canada (2013). Population-specific HIV/AIDS status report: People living with HIV/AIDS.

8. Millard, T., Elliott, J., & Girdler, S. (2013). Self-management education programs for people living with HIV/AIDS: A systematic review. *AIDS Patient Care STDS, 27*(2), 103-113, doi:10.1089/apc.2012.0294.

9. Swendeman, D., Ingram, B. L., & Rotheram-Borus, M. J. (2009). Common elements in self-management of HIV and other chronic illnesses: an integrative framework. *AIDS Care, 21*(10), 1321-1334, doi:10.1080/09540120902803158.

10. Degroote, S., Vogelaers, D., & Vandijck, D. (2014). What determines health-related quality of life among people living with HIV: an updated review of the literature. *Archives of Public Health, 72*(1), 1-10. doi:10.1186/2049-3258-72-40

11. Reynolds, R., Dennis, S., Hasan, I., Slewa, J., Chen, W., Tian, D., et al. (2018). A systematic review of chronic disease management interventions in primary care. *BMC Family Practice, 19*(1), 11, doi:10.1186/s12875-017-0692-3.

12. Zwar, N., Harris, M., Griffiths, R., Roland, M., Dennis, S., Powell Davies, G., et al. (2006). A systematic review of chronic disease management.

13. Lorig, K. R., & Holman, H. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26*(1), 1-7, doi:10.1207/s15324796abm2601_01.

14. Lenzen, S. A., van Dongen, J. J., Daniels, R., van Bokhoven, M. A., van der Weijden, T., & Beurskens, A. (2016). What does it take to set goals for self-management in primary care? A qualitative study. [Research Support, Non-U.S. Gov't]. *Family Practice, 33*(6), 698-703.

15. Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *JAMA, 288*(19), 2469-2475.

16. Blakeman, T., Macdonald, W., Bower, P., Gately, C., & Chew-Graham, C. (2006). A qualitative study of GPs' attitudes to self-management of chronic disease. *The British Journal of General Practice : The journal of the Royal College of General Practitioners, 56*(527), 407-414.

17. Buls, P. (2009). Non-adherence versus goal mismatch: Which one is it? *Home Healthcare Nurse, 27*(10), 630-634, doi:https://dx.doi.org/10.1097/01.NHH.0000364187.14968.cf.

18. Newbould, J., Burt, J., Bower, P., Blakeman, T., Kennedy, A., Rogers, A., et al. (2012). Experiences of care planning in England: Interviews with patients with long term conditions. [Research Support, Non-U.S. Gov't]. *BMC Family Practice, 13*, 71, doi:https://dx.doi.org/10.1186/1471-2296-13-71.

19. van Seben, R., Smorenburg, S. M., & Buurman, B. M. (2019). A qualitative study of patient-centered goal-setting in geriatric rehabilitation: Patient and professional perspectives. *Clinical Rehabilitation, 33*(1), 128-140, doi:https://dx.doi.org/10.1177/0269215518791663.

20. Raia, A. P. (1965). Goal setting and self-control: An empirical study. *Journal of Management Studies, 2*(1), 34-53.

21. Mayo, N. E. (2015). *Dictionary of quality of life and health outcome measurement* (First ed.). Milwaukee: International Society of Quality of Life Research (ISOQOL).

22. Mayo, N. E. (2016). Stroke Rehabilitation at Home: Lessons Learned and Ways Forward. *Stroke, 47*, 1685-1691, doi:10.1161/STROKEAHA.116.011309.

23. Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., et al. (2006). Lost in knowledge translation: Time for a map? *Journal of Continuing Education in the Health Professions, 26*(1), 13-24, doi:10.1002/chp.47.

24. Mayo, N. E., Brouillette, M. J., Fellows, L. K., & Positive Brain Health Now Investigators (2016). Understanding and optimizing brain health in HIV now: Protocol for a longitudinal cohort study with multiple randomized controlled trials. *BMC Neurology, 16*(8), doi:10.1186/s12883-016-0527-1.

25. Lam, A., Mayo, N. E., Scott, S., Brouillette, M. J., & Fellows, L. K. (2019). HIV-Related Stigma Affects Cognition in Older Men Living With HIV. *Journal of Acquired Immune Deficiency Syndromes: JAIDS, 80*(2), 198-204, doi:10.1097/qai.0000000000001898.

26. Mayo, N. E., Brouillette, M. J., Scott, S. C., Harris, M., Smaill, F., Smith, G., et al. (2019). Relationships between cognition, function, and quality of life among HIV+ Canadian men. *Quality of Life Research*, doi:10.1007/s11136-019-02291-w.

27. Wilson, I. B., & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA, 273*(1), 59-65.

28. Kuspinar, A., Finch, L., Pickard, S., & Mayo, N. E. (2014). Using existing data to identify candidate items for a health state classification system in multiple sclerosis. *Qual Life Res, 23*(5), 1445-1457, doi:10.1007/s11136-013-0604-5.

29. Rosenzveig, A., Kuspinar, A., Daskalopoulou, S. S., & Mayo, N. E. (2014). Toward patient-centered care: a systematic review of how to ask questions that matter to patients. *Medicine, 93*(22).

30. Guzman, N., & Vijayan, V. (2019). HIV-associated Lipodystrophy. In *StatPearls [Internet]*. Treasure Island (FL): StatPearls Publishing.

31. de Waal, R., Cohen, K., & Maartens, G. (2013). Systematic Review of Antiretroviral-Associated Lipodystrophy: Lipoatrophy, but Not Central Fat Gain, Is an Antiretroviral Adverse Drug Reaction. *PLoS ONE [Electronic Resource], 8*(5), e63623., doi: https://doi.org/10.1371/journal.pone.0063623.

32. Mozafarinia, M., Rajabiyazdi, F., Brouillette, M. J., Fellows, L. K., & NE., M. (2020). Development and Usability of a Feedback Tool, "My Personal Brain Health Dashboard", to Improve Setting of Self-Management Goals Among People Living with HIV in Canada. https://osf.io/3gzcx/.

33. Brouillette, M. J., Fellows, L. K., Finch, L., Thomas, R., & Mayo, N. E. (2019). Properties of a brief assessment tool for longitudinal measurement of cognition in people living with HIV. *PLoS ONE [Electronic Resource], 14*(3), e0213908, doi:10.1371/journal.pone.0213908.

34. Robbins, T. W., James, M., Owen, A. M., Sahakian, B. J., Lawrence, A. D., McInnes, L., et al. (1998). A study of performance on tests from the CANTAB battery sensitive to frontal lobe dysfunction in a large sample of normal volunteers: implications for theories of executive functioning and cognitive aging. Cambridge Neuropsychological Test Automated Battery. *Journal of International Neuropsychological Society, 4*(5), 474-490.

35. Modirrousta, M., & Fellows, L. K. (2008). Dorsal medial prefrontal cortex plays a necessary role in rapid error prediction in humans. *Journal of Neuroscience, 28*(51), 14000-14005, doi:10.1523/jneurosci.4450-08.2008.

36. Nasreddine, Z. S., Phillips, N. A., Bedirian, V., Charbonneau, S., Whitehead, V., Collin, I., et al. (2005). The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society, 53*(4), 695-699, doi:10.1111/j.1532-5415.2005.53221.x.

37. Figueiredo, S., Morais, J. A., & Mayo, N. E. (2017). Managing mobility outcomes in vulnerable seniors (MMOVeS): A randomized controlled pilot study. [Randomized Controlled Trial]. *Clinical Rehabilitation, 31*(12), 1604-1615, doi:https://dx.doi.org/10.1177/0269215517705941.

38. The pandas development team (2020, March 18). pandas-dev/pandas: Pandas. (1.0.3 (Version v1.0.3) ed.): Zenodo.

39. Bird, S., Loper, E., & Ewan, K. (2009). Natural Language Processing with Python. O'Reilly Media Inc.

40. Millard, T., Elliott, J., & Girdler, S. (2013). Self-management education programs for people living with HIV/AIDS: a systematic review. *AIDS patient care and STDs, 27*(2), 103-113, doi:10.1089/apc.2012.0294.

41. Zimbudzi, E., Lo, C., Misso, M. L., Ranasinha, S., Kerr, P. G., Teede, H. J., et al. (2018). Effectiveness of self-management support interventions for people with comorbid diabetes and chronic kidney disease: a systematic review and meta-analysis. [Meta-Analysis Review]. *Systematic Reviews, 7*(1), 84, doi:https://dx.doi.org/10.1186/s13643-018-0748-z.

42. Coulter, A., Entwistle, V. A., Eccles, A., Ryan, S., Shepperd, S., & Perera, R. (2015). Personalised care planning for adults with chronic or long-term health conditions. [Meta-

Analysis Research Support, Non-U.S. Gov't Review Systematic Review]. *Cochrane Database of Systematic Reviews*(3), CD010523, doi:https://dx.doi.org/10.1002/14651858.CD010523.pub2.

43. Raja, U., Mitchell, T., Day, T., & Hardin, J. M. (2008). Text mining in healthcare. Applications and opportunities. *J Healthc Inf Manag, 22*(3), 52-56.
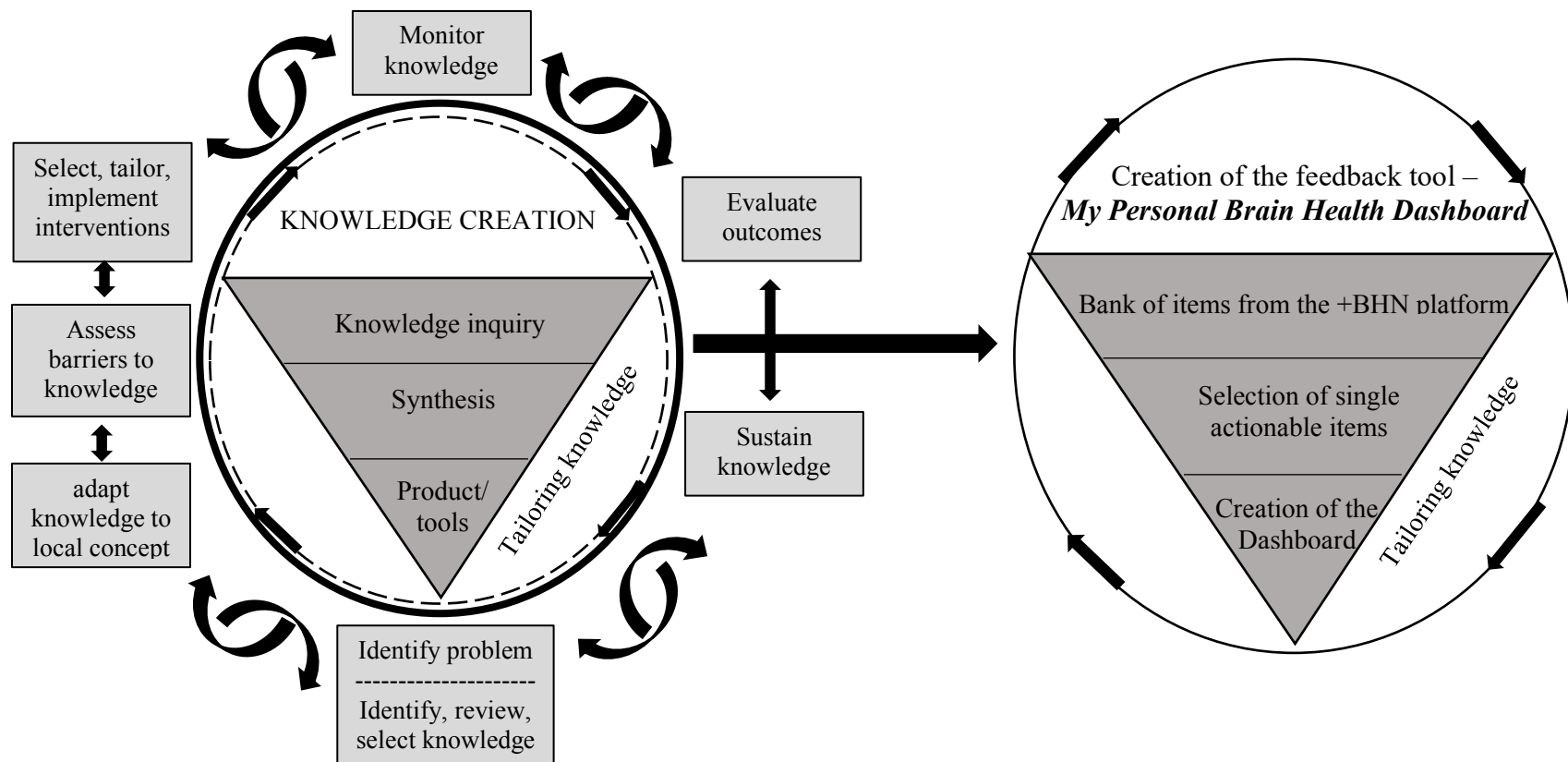
Figure 1 Knowledge-to-Action Cycle, Graham et al. [23]. The picture on the right shows the steps involved in the generation of the Dashboard inspired by the knowledge creation phase of the framework
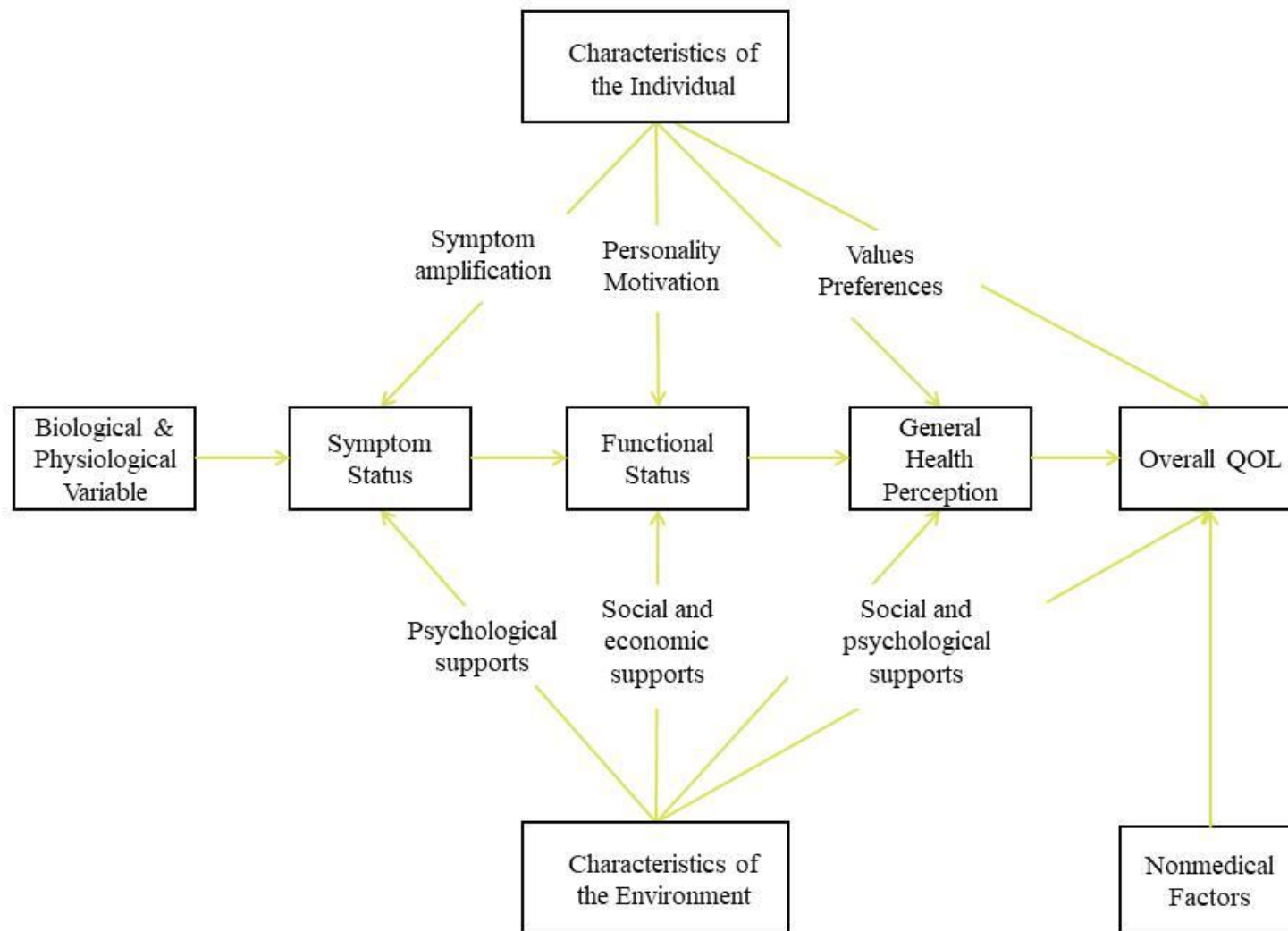
Figure 2 Wilson-Cleary outcome model. Adapted from Wilson and Cleary [27]

Dashboard Brain Health Now – First and most recent visit

Participant Number: 10-002 First visit: 29-OCT-2013 Most recent visit: 13-JAN-2016			
Profile	**Your first visit**	**Your most recent visit**	**Target**
Visit number	1	4	
Cognitive test score	Excellent	Good	**Excellent**
Self-reported perception of cognition	Good	-	**Excellent**
Able to concentrate	A moderate amount	A moderate amount	**Very much to extreme**
Negative feelings (blue mood, despair, anxiety, depression)	Quite often	Seldom	**Never to seldom**
Time feeling worn out	A little	Some	**None to a little**
Feeling rested after waking up	Never	Never	**Often to always**
Pain	None	None	**None to mild**
Limitation in physical activities			
Climbing several stairs	Limited a little	Not limited	**Not limited**
Walking more than a kilometer	Limited a little	Limited a little	**Not limited**
Vigorous activities	Limited a little	Limited a little	**Not limited**
Health rating	Very good	Very good	**Excellent, very good**
Quality of life	Good	Good	**Good, very good**
Body mass index	27	25	**Between 19 and 25**
Waist circumference	87	84	**Less than 102 cm**
The green boxes indicate where you have met the target **Number of positive elements at my first visit = 6** **Number of positive elements at my most recent visit = 7**			

Figure 3 First version of the Dashboard

Your Personal Brain Health Profile

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 a computer test 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 or close your values were compared to the optimal values. You can find the colors codes at the bottom of the Dashboard.

You might find that your status for some of the items on the Dashboard have 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:

	Items on your Dashboard	How they were measured?
1	Cognitive test score	This was evaluated by a computer test.
2	Your evaluation of your memory	You filled out a questionnaire and answered questions about your memory status.
3	Able to concentrate	You were asked to think about the last 2 weeks and answer how well are you able to concentrate.
4	Negative feelings (blue mood, despair, anxiety, depression)	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.
5	Feeling lonely	You were asked whether or not you find yourself feeling lonely.
6	Time feeling worn out	You were asked to think about the last 4 weeks and answer how much of the time did you feel worn out.
7	Feeling rested after waking up	You filled out a questionnaire with focus on your sleep status.
8	Your pain rating	You were asked to think about the last 4 weeks and answer how much bodily pain did you have.
9	Climbing several stairs	You were asked how much you find yourself limited in climbing several stairs.
10	Walking more than a kilometer	You were asked how much you find yourself limited in walking more than a kilometer.
11	Vigorous activities	You were asked how much you find yourself limited in doing vigorous activities.
12	Weight to height ration (BMI)	We measured your weight and your height, and this value shows whether your weight in proportion to your height is healthy or not.
13	Smoking	You were sked if you are a current smoker.
14	Health rating	You were asked, in general how would you say your health is?
15	Quality of life	You were asked how you would rate your quality of life?

See next page for your "Personal Brain Health Dashboard"

Figure 4 – A Last version of the Dashboard

RAIN HEALTH NOW : **Your Personal Brain Health Profile**

Participant Number:10-002			
Important Brain Health Areas	**Your first visit**	**Your most recent visit**	**Optimal**
Visit date	October 29, 2013	January 13, 2016	
Cognitive test score	Fair	Good	**Excellent**
Your evaluation of your memory	Good	.	**Excellent**
Able to concentrate	A moderate amount	A moderate amount	**Very much to extreme**
Negative feelings (blue mood, despair, anxiety, depression)	Quite often	Seldom	**Never or seldom**
Feeling lonely	Sometimes	Sometimes	**Almost never**
Time feeling worn out	A little	Some	**None to a little**
Feeling rested after waking up	Never	Never	**Often or always**
Your pain rating	None	None	**None to mild**
Climbing several stairs	Limited a little	Not limited	**Not limited**
Walking more than a kilometer	Limited a little	Limited a little	**Not limited**
Vigorous activities	Limited a little	Limited a little	**Not limited**
Weight to height ratio (BMI)	27	25	**Between 19 and 25**
Smoking	Smoking	Smoking	**Not smoking**
Health rating	Very good	Very good	**Excellent, very good**
Quality of life	Good	Good	**Good, very good**

▢ **The green boxes indicate areas where you are in the optimal state**
▢ **The neutral boxes 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 = 4
Number of optimal areas at my most recent visit = 6

Figure 4 – B Last version of the Dashboard

95

Figure 5 Word visualization for informed (i.e., received the Dashboard) and uninformed (i.e., did not receive the Dash- board) goals

96

Table 1 Example of the actionable versus non-actionable outcomes derived from the BHN platform

Actionable outcomes	**Definition:** ▪ Items that the individual can proactively set goals for and make action plans given their preferences and tolerance with or without having direction from the health care team. These items can be measured by setting SAMRT goals.
	Examples: ▪ Limitation in climbing up stairs ▪ Feeling rested after waking up ▪ Ability to concentrate
Non-actionable outcomes	**Definition:** ▪ Items that are too broad to set specific goals. ▪ Items that are too idiomatic to be acted upon ▪ Items that require interpretation from the health care team. SMART goals could be set for some of these outcomes but under supervision and follow-up of the health care team.
	Example: ▪ How healthy is your physical environment? ▪ Are you bothered by butterflies in your stomach? ▪ How much do you worry about death? ▪ Physiological/radiological findings (e.g., biomarkers, imaging, etc.)

Table 2 Items included in the Dashboard, resource tools, and response options on the original questionnaire

	Dashboard items	Questionnaire/ Tool	Response options on the questionnaire	Cut-offs for Color codes$^\Psi$
1	Cognitive test score	B-CAM test		Excellent >23
				Good 20-23
				Fair <20
2	Your evaluation of your memory*	PDQ (20 items)	☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Almost always	Excellent
		C3Q score (18 items)	☐ Frequently (almost every day) ☐ Sometimes (once a week) ☐ Rarely (once a month or less)	Good
				Fair
3	Able to concentrate	WHOQOL / Q11	In the last two weeks, how well are you able to concentrate? ☐ Not at all ☐ A little ☐ A moderate amount ☐ Very much ☐ Extremely	Very much to extreme
				A moderate amount
				A little or not at all
4	Negative feelings (blue mood, despair, anxiety, depression)	WHOQOL / Q31	In the last two weeks, how often do you have negative feelings such as blue mood, despair, anxiety, depression? ☐ Never ☐ Seldom ☐ Quite often ☐ Very often ☐ Always	Never or seldom
				Quite often
				Very often or always
5	Feeling lonely	OARS: Social support / Q5	Do you find yourself feeling lonely? ☐ Quite often ☐ Sometimes ☐ Almost never	Almost never
				Sometimes
				Quite often
6	Time feeling worn out	SF 36 – vitality / Q7	In the last four weeks, how much of the time did you feel worn out? ☐ All of the time ☐ Most of the time ☐ A good bit of the time ☐ Some of the time ☐ A little of the time ☐ None of the time	None to a little
				Some to a good bit of the time
				Most or all of the time
7	Feeling rested after waking up	Sleep questionnaire	☐ Never ☐ Often ☐ Always	Always
				Often
				Never
8	Your pain rating	SF 36 / Q4	How much bodily pain have you had during the past 4 weeks? ☐ None ☐ Very mild ☐ Mild ☐ Moderate ☐ Severe ☐ Very severe	None to mild
				Moderate
				Severe to very severe
9	Climbing several stairs	SF 36 / Q4d	☐ Yes, limited a lot ☐ Yes, limited a little ☐ No, not limited at all	Not limited
				Limited a little
				Limited a lot
10	Walking more than a kilometer	SF 36 / Q4g	☐ Yes, limited a lot ☐ Yes, limited a little ☐ No, not limited at all	Not limited
				Limited a little
				Limited a lot
11	Vigorous activities	SF 36 / Q4a	☐ Yes, limited a lot ☐ Yes, limited a little ☐ No, not limited at all	Not limited
				Limited a little
				Limited a lot
12	Weight to height ratio (BMI)	-		Between 19 & 25
				26-30
				>30
13	Smoking	-	Are you a current smoker? ☐ Yes ☐ No	Not smoking
				Smoking
14	Health rating	SF 36 / Q1	In general, would you say your health is: ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor	Excellent, very good
				Good
				Fair to poor
15	Quality of life	WHOQOL / Q1	How would you rate your quality of life? ☐ Very poor ☐ Poor ☐ Neither poor nor good ☐ Good ☐ Very good	Very good, good
				Neither poor nor good
				Poor, very poor

B-CAM: Brief cognitive ability measure - a computer-based test measuring cognitive function; PDQ: Perceived Deficits Questionnaire; C3Q: Communicating Cognitive Concerns in HIV Questionnaire (a new HIV-specific self-report measure of cognitive ability); WHOQOL: World Health Organization Quality of Life; OARS: Older Americans Resources and Services, SF 36: Short From health survey.

$^\Psi$ The cut-offs are presented in different shades from darker to lighter. The darker grey color represents the optimal level. The lighter grey represents below optimal but not too far away; and the "white" represents further away from the optimal. On the Dashboard these colors are as "green", "beige", and "orange" respectively.

* Self-report measures of cognition have been used. Some participants answered to the PDQ as C3Q was developed during the course of the study. The total scores for both questionnaires have been used to provide the feedback result on the Dashboard.

Table 3 Saturation grid for items arose during cognitive debriefing

Items / Participants	Pain	BMI	Color codes	Needed more context	Cognitive test score	Smoking
1	▓	▓	▓	▓		
2			▓	▓		
3				▓		
4					▓	
5		▓	▓	▓		
6					▓	
7	▓			▓		
8		▓		▓		
9	▓			▓	▓	
10	▓		▓			▓
11						▓
12						
13					▓	
14						
15						

Saturation occurs when the full range of the problems and interpretations are identified and explained. The grey zone is where there was a difficulty in understanding/questions/ or comments about the item. As it has been shown in this grid, no new comments/concerns were mentioned by the last four participants.

Table 4 Comparison of goal quality among three groups

Groups	Supervised (n=10)	Informed (n=10)	Uninformed (n=10)
Number of goals	10	42	33
Specific nouns	22	50	34
Actionable verbs	18	53	38
Units of measurement	8	12	7
Time-bound	16	8	16
Total number of neutral verbs	5	34	33
Mean number of neutral verbs (per person goal)	5	8.7	15
Total number of specific words	71	157	114
Σ mean number of specific words (per person goal)	71	43.35	51.75
Rate of specific goals*	7.1	1.03	1.6

Note: Informed group wrote goals based on the given Dashboard. The Dashboard was not their personal profile.

*Σ mean number of specific words (per person goal)/ number of goals

CHAPTER 6: Integration of Manuscripts II & III

Research Objectives of Manuscript II

1- To develop a personalized health outcome profile as a feedback tool to improve self-management in people living with chronic conditions such as HIV.

2- To identify areas that would improve the interpretability and usefulness of the feedback tool for setting specific goals.

Research Objectives of Manuscript III

To provide a protocol for a blinded pragmatic randomized controlled trial with the aim 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.

Integration of Manuscript II and III

Manuscript II presented a step-by-step approach for the development of "*My Personal Brain Health Dashboard*" – a feedback tool designed to communicate individuals' status on modifiable areas influencing person's quality of life. Report of cognitive debriefing included relevant details on improving the precision of the developed feedback tool (hereafter Dashboard) by customizing the content and graphic design. The content and layout of the Dashboard was intended to help improve individuals' ability to reflect on their own health status, make choices, and set self-management goals that would eventually lead to improved health outcomes. To capture the real-life effect of an intervention, pragmatic trials are well suited. The +BHN study with a cohort multiple randomized controlled trial (cmRCT) design would allow inclusion of individuals from the targeted population to whom the efficacy findings will be applied in the real world. Also, if goal setting is to be tested outside face-to-face clinical settings and at population-base, it is equally important to solicit a pragmatic approach towards its measurement. Text mining

techniques are known to provide context around unstructured patient-generated data. The subsequent manuscript defines in detail the plannig for a blinded pragmatic randomized controlled trial (RCT) designed to test the effectiveness of the Dashboard on setting specific self-management goals among HIV+ individuals in Canada.

CHAPTER 7 : Manuscript III

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

Maryam Mozafarinia*[1,8], Fateme Rajabiyazdi[2,3], Marie-Josée Brouillette[4,8], Lesley K. Fellows[5], Bärbel Knäuper[6], and Nancy E. Mayo[1,7,8]

[1]Division of Experimental Medicine, McGill University, [2]Department of Surgery, [3]Steinberg Bernstein Centre for Minimally Invasive Surgery and Innovation, [4]Department of Psychiatry, [5]Department of Neurology and Neurosurgery and Chronic Viral Illness service, [6]Department of Psychology, [7]Department of Medicine and School of Physical and Occupational Therapy, [8]Center for Outcome research & Evaluation, McGill University, Montreal, Canada

Correspondence author:

Maryam Mozafarinia, RN, BScN, MScN,
Division of Experimental Medicine, Faculty of Medicine, McGill University &
Center for Outcome Research and Evaluation (CORE)
McGill University Health Centre Research Institute
5252 de Maisonneuve, Office 2C:13
Montréal, Québec, H4A 3S5
E-mail: maryam.mozafarinia@mail.mcgill.ca

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 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, registered on 25th November 2019.

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

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

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,[3-5] the focus is shifting to the issues adults living with HIV are facing as they age, [6] such as a higher risk of developing other chronic diseases.[2] 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.[7] 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.[8]

Multiple chronic conditions can interact to diminish a person's well-being and quality of life.[9] 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.[10]

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),[11] 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.[12,13] 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.[14]

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.[15-20] Patient-centered goals are defined as goals set with patients actively engaged, through discussing goals, setting plans, and evaluating their condition afterwards.[21]

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.[22] 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.[23-25] 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.[26] 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"[27]. 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 interfered with writing high quality goals.[28] As self-management approaches have mostly been implemented as part of clinical programs, the recommendations have been tailored to the individual's cognitive capacity.[29] 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.[30] 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.[31] 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.[32] 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.[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 25 November 2019 (Clinicaltrials.gov NCT04175795).

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 had 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.[30]

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, survey links (available in French and English), their unique access code, and the link to access to a specialized web-based goal setting platform 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*[35]), 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.[36] It involves providing feedback [about modifiable contributors of health and quality of life] by sending participants their personalized health profiles. As part of the knowledge translation plan,

111

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.

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*[1] *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).[39]

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

---

[1] SMART - A widely used criteria to guide setting goals which stands for specific, measurable, action-planned, realistic, and time-bound goals.

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*[35]). 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 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*.[35]

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 (E(Rate of Goal Specificity)) = (groups) + (Gender) + (B-CAM scores) + (groups*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., $e^{\beta 0}$) and collaboratively set goals[2] [40] (i.e., $e^{\beta 1}$). 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%,[41] 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

---

[2] Permission to access the data was granted by contacting the primary investigator

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 publically available and published in peer reviewed journals and disseminated at relevant conferences and meetings at the completion of the study. This study is novel 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

<OSF>: <Goal Setting in HIV>, <DOI 10.17605/OSF.IO/EXUJM>. <License: CC0 1.0 Universal >.[35]

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

<OSF>: SPIRIT checklist for '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', DOI 10.17605/OSF.IO/EXUJM. License: CC0 1.0 Universal.[35]

REFERENCES

1.   Public Health Agency of Canada. *Population-specific HIV/AIDS status report: People living with HIV/AIDS.* 2013.

2.   Deeks SG, Lewin SR, Havlir DV. The end of AIDS: HIV infection as a chronic disease. *Lancet.* 2013;382(9903):1525–33.

3.   Samji H, Cescon A, Hogg RS, et al. Closing the gap: Increases in life expectancy among treated HIV-positive Individuals in the United States and Canada. *PLoS ONE.* 2013;8(12):e81355.

4.   Katz IT, Maughan-Brown B. Improved life expectancy of people living with HIV: Who is left behind? *Lancet HIV.* 2017;4(8):PE324-E26.

5.   World Health Organization. HIV: From a devastating epidemic to a manageable chronic disease. In: *Ten years in public health, 2007–2017: Report by Dr Margaret Chan, Director-General, World Health Organization.* Geneva: World Health Organization, Licence: CC BY-NC-SA 3.0 IGO.; 2017.

6.   Hawkins KL, Brown TT, Margolick JB, Erlandson KM. Geriatric syndromes: New frontiers in HIV and sarcopenia. *AIDS.* 2017;31(Suppl 2):S137-S46.

7.   Serrano-Villar S, Gutiérrez F, Miralles, et al. Human Immunodeficiency Virus as a chronic disease: Evaluation and management of non-Acquired Immune Deficiency Syndrome-defining conditions. *Open Forum Infect Dis.* 2016;3(2):ofw097.

8.   Brothers TD, Rockwood K. Biologic aging, frailty, and age-related disease in chronic HIV infection. *Curr Opin HIV AIDS.* 2014;9(4):412-18.

9.   Public Health Agency of Canada. *How healthy Canadians are? A trend analysis of the health of Canadians from a healthy living and chronic disease perspective.* Report. Public Health Agency of Canada; 2017.

10.   Bernell S, Howard SW. Use your words carefully: What is a chronic disease? *Front Public Health.* 2016;4.

11.   Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. *Milbank Q.* 1996;74(4):511-44.

12.   Reynolds R, Dennis S, Hasan I, et al. A systematic review of chronic disease management interventions in primary care. *BMC Fam Pract.* 2018;19(1):11.

13.   Zwar N, Harris M, Griffiths R, et al. A systematic review of chronic disease management. 2006. https://openresearch-repository.anu.edu.au/bitstream/1885/119226/3/final_25_zwar_pdf_85791.pdf. Accessed March 4, 2019.

14.   Lorig KR, Holman H. Self-management education: History, definition, outcomes, and mechanisms. *Ann Behav Med.* 2003;26(1):1-7.

15.   Anuruang S, Hickman LD, Jackson D, Dharmendra T, Van Balen J, Davidson PM. Community-based interventions to promote management for older people: An integrative review. *J Clin Nurs.* 2014;23(15-16):2110-20.

16.   Lopez-Vargas PA, Tong A, Howell M, Craig JC. Educational interventions for patients with CKD: A systematic review. *Am J Kidney Dis.* 2016;68(3):353-70.

17. Vermunt N, Harmsen M, Westert GP, Olde Rikkert MGM, Faber MJ. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: A systematic review. *BMC geriatr.* 2017;17(1):167.

18. Kuo CC, Wang RH. Appraisal of the application of empowerment elements and strategies: The example of chronic metabolic diseases. *Hu Li Za Zhi.* 2013;60(1):78-86.

19. Parke HL, Epiphaniou E, Pearce G, et al. Self-management support interventions for stroke survivors: A systematic meta-review. *PLoS ONE.* 2015;10 (7): e0131448.

20. Van Hecke A, Heinen M, Fernandez-Ortega P, et al. Systematic literature review on effectiveness of self-management support interventions in patients with chronic conditions and low socio-economic status. *J Adv Nurs.* 2017;73(4):775-93.

21. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *JAMA.* 2002;288(19):2469-75.

22. Davis S, Abidi SS, Stewart S. A compositional personalization approach for designing personalized patient educational interventions for cardiovascular risk management. *Stud Health Technol Inform.* 2010;160(Pt 1):629-33.

23. Dineen-Griffin S, Garcia-Cardenas V, Williams K, Benrimoj SI. Helping patients help themselves: A systematic review of self-management support strategies in primary health care practice. *PLoS ONE.* 2019;14(8):e0220116.

24. Teasdale N, Elhussein A, Butcher F, et al. Systematic review and meta-analysis of remotely delivered interventions using self-monitoring or tailored feedback to change dietary behavior. *Am J clin Nutr.* 2018;107(2):247-56.

25. Krebs P, Prochaska JO, Rossi JS. A meta-analysis of computer-tailored interventions for health behavior change. *Prev Med.* 2010;51(3):214-21.

26. Kreuter MW, Wray RJ. Tailored and Targeted Health Communication: Strategies for Enhancing Information Relevance. *Am J Health Behav.* 2003;27(1):227-32.

27. Christensen C, Fogg R, Waldeck A. Health for hire: Unleashing patient potential to reduce chronic disease costs. 2017. https://www.christenseninstitute.org/wp-content/uploads/2017/10/Health-for-Hire.pdf. 2019.

28. Schouten J, Cinque P, Gisslen M, Reiss P, Portegies P. HIV-1 infection and cognitive impairment in the cART era: a review. *AIDS.* 2011;25(5):561-75.

29. Baird C, Lovell J, Johnson M, Shiell K, Ibrahim JE. The impact of cognitive impairment on self-management in chronic obstructive pulmonary disease: A systematic review. *Respir Med.* 2017;129:130-9.

30. Mayo NE, Brouillette MJ, Fellows LK, Positive Brain Health Now Investigators. Understanding and optimizing brain health in HIV now: Protocol for a longitudinal cohort study with multiple randomized controlled trials. *BMC neurol.* 2016;16(8).

31. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA.* 1995;273(1):59-65.

32. Mayo NE, Brouillette M-J, Scott SC, et al. Relationships between cognition, function, and quality of life among HIV+ Canadian men. *Qual Life Res.* 2020;29(1):37-55.

33. Lam A, Mayo NE, Scott S, Brouillette MJ, Fellows LK. HIV-Related Stigma Affects Cognition in Older Men Living With HIV. *J Acquir Immune Defic Syndr.* 2019;80(2):198-204.

34.   Mayo NE, Brouillette MJ, Scott SC, et al. Relationships between cognition, function, and quality of life among HIV+ Canadian men. *Qual Life Res.* 2019.

35.   Mozafarinia M, Rajabiyazdi F, Brouillette MJ, Fellows LK, Knäuper B, NE. M. Goal Setting in HIV. osf.io/exujm. 2020.

36.   Graham ID, Logan J, Harrison MB, et al. Lost in knowledge translation: Time for a map? *J Contin Educ Health Prof.* 2006;26(1):13-24.

37.   Kuspinar A, Finch L, Pickard S, Mayo NE. Using existing data to identify candidate items for a health state classification system in multiple sclerosis. *Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation.* 2014;23(5):1445-57.

38.   Rosenzveig A, Kuspinar A, Daskalopoulou SS, Mayo NE. Toward patient-centered care: a systematic review of how to ask questions that matter to patients. *Medicine (Baltimore).* 2014;93(22).

39.   Stevens A, Beurskens A, Koke A, van der Weijden T. The use of patient-specific measurement instruments in the process of goal-setting: A systematic review of available instruments and their feasibility. *Clin Rehabil.* 2013;27(11):1005-19.

40.   Figueiredo S, Morais JA, Mayo NE. Managing mobility outcomes in vulnerable seniors (MMOVeS): A randomized controlled pilot study. *Clin Rehabil.* 2017;31(12):1604-15.

41.   Wengrzik J, Bosnjak M, Lozar Manfreda K. Web surveys versus other survey modes: An updated meta-analysis comparing response rates. Paper presented at: General Online Research Conference 2016; Dresden, Germany. 2016.
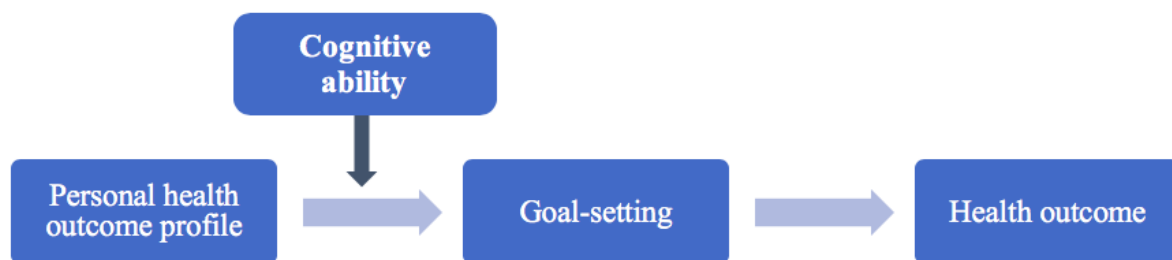
Figure 1. Conceptual model.
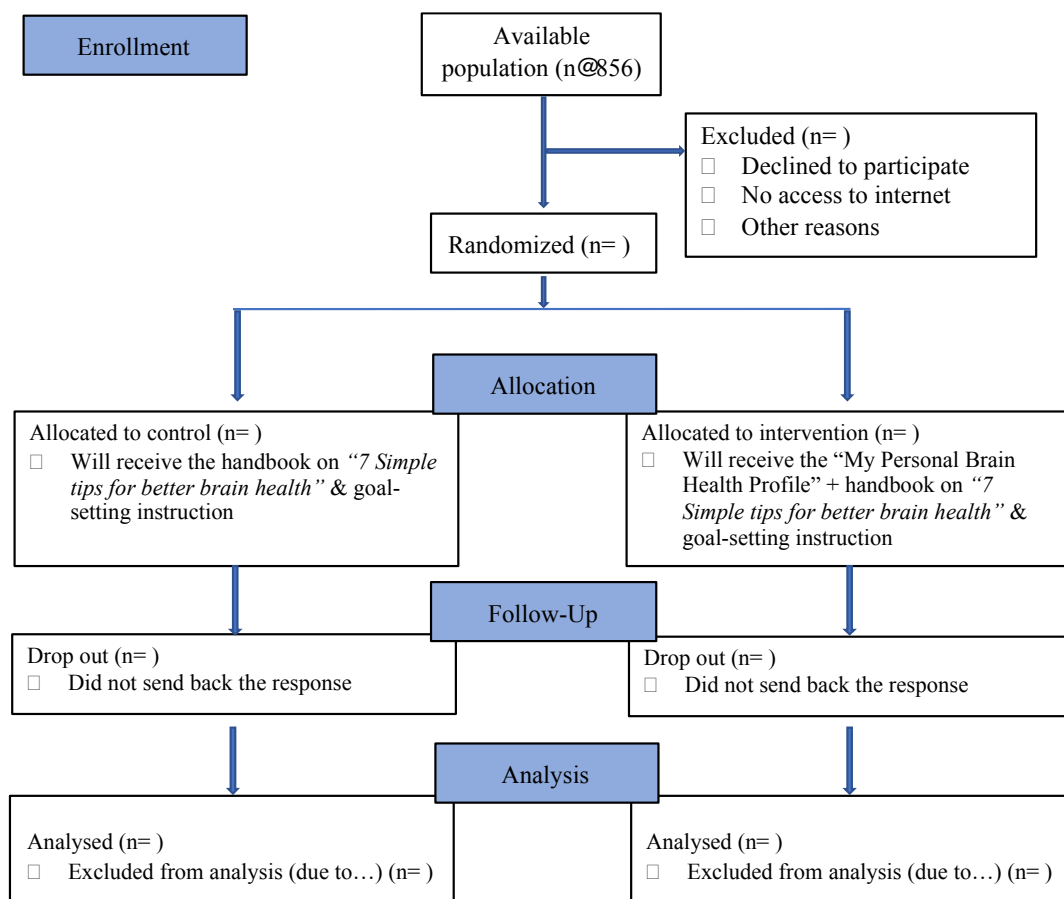
Figure 2. Flow diagram for goal setting trial in HIV cohort.

A

Your Personal Brain Health Profile

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 or close your values were compared to the optimal values. You can find the colors 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:

	Items on your Dashboard	How they were measured?
1	Cognitive test score	This was evaluated by a computer test.
2	Your evaluation of your memory	You filled out a questionnaire and answered questions about your memory status
3	Able to concentrate	You were asked to think about the last 2 weeks and answer how well are you able to concentrate?
4	Negative feelings (blue mood, despair, anxiety, depression)	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?
5	Feeling lonely	You were asked whether or not you find yourself feeling lonely?
6	Time feeling worn out	You were asked to think about the last 4 weeks and answer how much of the time did you feel worn out?
7	Feeling rested after waking up	You filled out a questionnaire with focus on your sleep status
8	Your pain rating	You were asked to think about the last 4 weeks and answer how much bodily pain did you have?
9	Climbing several stairs	You were asked how much you find yourself limited in climbing several stairs?
10	Walking more than a kilometer	You were asked how much you find yourself limited in walking more than a kilometer?
11	Vigorous activities	You were asked how much you find yourself limited in doing vigorous activities?
12	Weight to height ratio (BMI)	We measured your weight and your height, and this value shows whether your weight in proportion to your height is healthy or not.
13	Smoking	You were sked if you are a current smoker?
14	Health rating	You were asked, in general how would you say your health is?
15	Quality of life	You were asked how you would rate your quality of life?

B

positive
BRAIN HEALTH NOW : **Your Personal Brain Health Profile**

Participant Number:10-002			
Important Brain Health Areas	**Your first visit**	**Your most recent visit**	**Optimal**
Visit date	October 29, 2013	January 13, 2016	
Cognitive test score	Excellent	Good	**Excellent**
Your evaluation of your memory	Good	.	**Excellent**
Able to concentrate	A moderate amount	A moderate amount	**Very much to extreme**
Negative feelings (blue mood, despair, anxiety, depression)	Quite often	Seldom	**Never or seldom**
Feeling lonely	Sometimes	Sometimes	**Almost never**
Time feeling worn out	A little	Some	**None to a little**
Feeling rested after waking up	Never	Never	**Often or always**
Your pain rating	None	None	**None to mild**
Climbing several stairs	Limited a little	Not limited	**Not limited**
Walking more than a kilometer	Limited a little	Limited a little	**Not limited**
Vigorous activities	Limited a little	Limited a little	**Not limited**
Weight to height ratio (BMI)	27	25	**Between 19 and 25**
Smoking	Smoking	Smoking	**Not smoking**
Health rating	Very good	Very good	**Excellent, very good**
Quality of life	Good	Good	**Good, very good**

■ The green boxes indicate areas where you are in the optimal state
■ The neutral boxes 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

Figure 3. My Personal Brain Health Profile.

CHAPTER 8: Integration of Manuscripts III & IV

Research Objectives of Manuscript III

To provide a protocol for a blinded pragmatic randomized controlled trial (RCT) with the aim 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.

Research Objectives of Manuscript IV

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.

Integration of Manuscript III and IV

Following the planning of the effectiveness study presented in manuscript III, goal data of participants in textual format was collected and analyzed. Manuscript IV presents the primary findings of the trial. The focal point of this manuscript is to estimate the specificity of self-management goals by means of text mining techniques. This approach was employed to test the potentials of text mining as a novel approach to measure goal specificity. When goals are set collaboratively (i.e., patient-clinician dyad), clinicians do their best to improve the goals as Specific, Measurable, Actionable, Realistic, and Time-bound (*SMART*) – making them more specific. For text mining algorithms to be able to detect these criteria, these data need to be defined and fed to the program. This process was done by developing a goal setting lexicon (also mentioned in manuscript I to III) which was updated continuously to now include some 1000 words representing *SMART* criteria. Details of text mining steps are also presented in the following manuscript.

CHAPTER 9 : Manuscript IV

Effectiveness of a Personalized Health Profile on Specificity of Self-Management Goals Among People Living with HIV in Canada: Findings from a Blinded Pragmatic Randomized Controlled Trial

Maryam Mozafarinia*[1,7], Fateme Rajabiyazdi[2], Marie-Josée Brouillette[3,7], Lesley K. Fellows[4], Bärbel Knäuper[5], and Nancy E. Mayo[1,6,7]

[1]Division of Experimental Medicine, [2]System and Computer Engineering, Faculty of Engineering and Design, Carlton University, Ottawa, Canada, [3]Department of Psychiatry, [5]Department of Neurology and Neurosurgery and Chronic Viral Illness service, [5]Department of Psychology, [6]Department of Medicine and School of Physical and Occupational Therapy, [7]Center for Outcome research & Evaluation, McGill University, Montreal, Canada

Correspondence author:

Maryam Mozafarinia, RN, BScN, MScN,
Division of Experimental Medicine, Faculty of Medicine, McGill University &
Center for Outcome Research and Evaluation (CORE)
McGill University Health Centre Research Institute
5252 de Maisonneuve, Office 2C:13
Montréal, Québec, H4A 3S5
E-mail: maryam.mozafarinia@mail.mcgill.ca

Abstract

Background: Goal setting is fundamental to self-management practice for people living with chronic conditions. Personalized outcome feedback is needed for goal setting, a requirement for behavior change. This report contributes to the understanding of the specificity of patient-formulated self-management goals by testing the effectiveness of a personalized health outcome profile. We aimed 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 was produced for individuals enrolled in a Canadian HIV Brain Health Now cohort study at cohort entry and at the last recorded visit. Participants were randomized (1:1) to receive or not "My Personal Brain Health Dashboard" prior to a goal setting exercise. Group assignment was known to trial staff but masked to investigators. Self-defined goals in free text were collected through an online platform. Intervention and control groups received instructions on goal setting and tips to improve brain health. Two reminders were sent one week apart (if responses were not received as expected). The primary outcomes were number, and specificity of the goals. Specificity was measured by total number of specific words (matched a developed lexicon) per person-words using text mining techniques and estimated by negative binomial regression. This trial is registered with ClinicalTrials.gov, NCT04175795.

Results: Of 350 participants initially approached, 176 were eligible and enrolled between Jan 13, 2020 and July 14, 2020 and randomly assigned to feedback (n=88) and control groups (n=88) . A total of 110 survey responses received and analyzed (56 in English/54 in French). Average number of goals was similar for both groups feedback and control group (3.7 vs 3.9). The

number of specific words used in the goals formulated by the intervention group was 642 and, for the control group, 739; 30% were specific and represented goal criteria. Specific nouns and actionable verbs were present to some extent and "measurable" and "time-bound" words were mainly missing. Negative binomial regression showed no difference in goal specificity among groups (RR = 0.93, 95% CI 0.78 – 1.10). Cognitive ability did not affect goal specificity (RR = 1.13, 95% CI 0.45, 2.82). There was a weak correlation between goal specificity and education (r = 0.21, 95% CI 0.02, 0.38) and cognition (r = 0.17, 95% CI -0.01, 0.35). Goals set by both groups overlapped in 8 areas and had little difference in rank.

Conclusion: Personal Brain Health Dashboards did not help with formulation of high-quality goals. Text mining has the potential to help with difficulties of goal evaluation outside of the face-to-face setting. With more data and use of learning models automated answers could be generated to provide a more dynamic platform.

Introduction

Chronic conditions are a challenging public health issue all around the world.[1] With an increasing number of people living and aging with chronic conditions, there is a major focus on a health care systems' approach to respond to patients' expectations and needs. Aside from long-term clinical monitoring, living with a chronic condition requires patients to adhere to many competing self-management tasks (e.g., modification of dietary habits, incorporation of physical activities).[2] Given that most daily management of chronic conditions is happening outside of the health care setting, increased attention has been given to the delivery of needs-based services and maximizing patients' potential to self-manage their condition.[3]

Treatment advances for HIV over the last four decades has transformed HIV to a long-term chronic condition.[4,5] People living with HIV are now experiencing the additional burden of multimorbidity due to long exposure to HIV, antiretroviral treatment, and aging with concomitant effect on health-related quality of life (HRQoL).[6] With the global progress in reaching and maintaining the UNAIDS 90-90-90 percent target (for the diagnosis, treatment, and viral suppression), the HIV community is now emphasizing HIV care to go beyond viral suppression only and has added good HRQoL as the fourth 90% target.[7] Self-management is fundamental to improvement in HRQoL as it is focused on delivering meaningful and tailored information to patients so that they can set health-related goals, and set in place appropriate action plans aimed to improve their health outcome over time.[8]

Self-management interventions which incorporated goal setting component have shown to be effective in increasing patients' progress towards better health outcomes in the context of chronic diseases.[9,10] A recent umbrella review[11] on goal setting identified that goal setting has mainly been studied as an add-on to other self-management components and makes a small contribution

to improving clinically relevant outcomes. Until now, studies of goal setting to improve health outcomes for people with chronic diseases have used a collaborative approach to goal setting as part of self-management intervention.

Time, energy, and active engagement of the patient and the clinician are key factors in forming an effective goal setting process.[12] With limited time allocation during clinic visits and biomedical topics competing with patients' priorities,[13] it is unclear how much goal setting exchange could be accomplished. Patient formulated 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 actions are difficult and can threaten achievement of targeted health outcomes.

Over the past decade, eHealth technology has helped with the delivery of educational and motivational self-management support. One possible strategy to empower patients to self-manage their condition is by structured communication of information about their health profile to stimulate the setting of specific goals.[14] Previous studies reported that personalized feedback helps with improvement of patients' adherence to risk-reducing behaviours (diet, physical activity).[15-17] Personalized rather than general feedback received more attention by patients as they could develop expectations according 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. The objective of this study was 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.

Methods

The protocol for this trial has been previously published.[19] We used the reporting guideline for pragmatic trials.[20]

Study design

This was a blinded, stratified, pragmatic randomized controlled trial.

Participants

This study was a sub-study of the BHN (Brain Health Now) study (http://brainhealthnow.org) – a multi-site Cohort Multiple Randomized Controlled Trial (cmRCT) across five HIV sites in Canada.[21] The BHN study is a prospective study. It started in 2013 and during its first phase until 2018, Positive Brain Health Now (+BHN), recruited and assessed (4 times, 9 months apart) over 800 HIV+ men and women. The BHN study is continuing with its phase II of five years, Action for Brain Health Now (ABHN), to cover the period until 2023 with annual follow-up. Participants for this study were HIV+ individuals who were enrolled in either phases of the BHN study with two assessments (first and most recent), agreed to be contacted for further sub-studies, and had access to the internet. Briefly, cohort members were adults of ≥ 35 years who were HIV+ for at least 1 year. People with dementia, co-morbidities affecting cognition, substance abuse, or life- threatening illnesses were excluded.

Procedures

All eligible participants were first contacted by the trial staff (i.e., designated research assistants) either by phone or e-mail. After providing and/or confirming their e-mail addresses, participants received an e-mail with trial information, their unique access code (token), and the link to access the goal setting survey platform (in French and English). The intervention group received their

personal health profile (hereafter Dashboard) via e-mail along with instructions on goal setting and tips to improve brain health. The control group received only the goal setting instructions and tips.

Data collection was was conducted over six months from January 2020 until mid-August 2020 through a web-based goal setting platform (LimeSurvey hosted on a McGill server). Upon electronically signing the consent form (*Extended data*)[22], participants were directed to the main page to write their goals (in free text) and answer questions that followed each goal. Participants were encouraged to think of the top 3 to 5 actions they would like to take to improve their health condition in the assigned boxes. Following each goal, a section was assigned for perceived barriers and enablers.

Participants were given a maximum of 2 weeks to answer and submit the survey (a reminder e-mail was sent after the first week). A second reminder e-mail was sent to those who did not answer the survey within the two weeks. Participants who did not answer to the survey after the second reminder were not 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 received their Dashboard via e-mail. Communication with participants were only via research assistants (either phone or email). There was no in-person visit for this project. Step by step instruction as to how fill out the survey was also made as a PDF file in English and French for participants who needed some guidance for filling out the survey. A brief post survey assessment for evaluation of intervention compliance was also conducted.

This study was approved by institutional research ethics (McGill University Health Centre Research Ethics Board, ABHN_Goals 2020-5728) and was registered as a trial on 25 November 2019 (ClinicalTrials.gov, NCT04175795).

Intervention

The intervention tested in this study was providing feedback on modifiable contributors of health and quality of life. For this goal, a Dashboard comprised of 15 different actionable items (selected from pre-existing validated measures with sufficient track record of validity) was developed for all BHN participants to cover information on brain health outcomes, health and quality of life ratings, and lifestyle factors (Figure 1). Details on the development and usability testing of the Dashboard has been published elsewhere.[23] The Dashboard deemed ideal as a feedback tool because 1) it was a summary of participants' 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, 2) results were color coded to facilitate comparison with the optimal range and identification of areas which were suboptimal, and 3) with the provision of optimal range and information of how items were measured, the Dashboard could be used as a self-assessment tool to help participants evaluate themselves according to their current perceived health status. Therefore, our hypothesis was that the Dashboard would potentially help participants to realize aspects of their life that are amenable to intervention and set achievable goals for.

Outcomes

We tested the hypothesis that providing feedback, using the Dashboard, results in formulation of more specific goals. The two main outcomes were the number and specificity of self-management goals. For goal specificity, text mining techniques were used. This outcome is reported as a discrete variable – number of specific words (matched to a developed lexicon) per person-words. It was expected that the intervention group will set more goals and have more words matching the lexicon than the control group. The numerator for this estimator was total

number of specific words per group; the denominator was the sum of cumulated number of words per person.

Regardless of goal setting approach (collaboratively, dictated, or patient-defined), *SMART criteria[24]* – Specific, Measurable, Actionable, Realistic, and Time-bound – has been widely used for goal formulation. There are no standardized and validated measuring criteria for goal formulation. To test goal quality at the population level where goals are self-defined and most often lack the structure and format of clinically *SMART* goals, techniques of text mining would appear to be well suited. In this study we used text mining techniques to extract and understand specific goal criteria from the textual data.

Text mining procedure

Python programming language and relevant libraries were used for the text mining process.

Preparation – Goal setting lexicon

Prior to starting the trial, an initial lexicon (i.e., start list of words; *Extended data)[22]* was created. The aim of lexicon was to help with identification of words that represent *SMART* criteria. Two separated lists of vocabularies were considered for each goal criteria. Words were chosen according to a developed guideline for this purpose (*extended data[22]*). For example, for S (specific), the definition was "a specific health concern or need of the person. The goal is clearly focused on the desired outcome/behaviour" so that the defined goal could simply answer "what does the person need/want?". For text mining purpose, the aim was to find concrete, well-defined nouns. Therefore, in the lexicon specific nouns versus ambiguous nouns were listed. Similar pattern was followed for the other criteria. Thus, the lexicon contained 8 categories (two for each criteria): one for words that convey vague information and another for words that make goals

more specific. Word classification was a census-based decision-making process, and the lexicon was reviewed by a multidisciplinary group of researchers and clinicians familiar with goal setting.

Next, to enrich the lexicon synonyms were found using lemmatization function to reach the root (i.e., word's lemma) of the words followed by "*synset ()*" function. For this purpose, we used NLTK[1] corpus reader (i.e., Wordnet) for English[25] and French[26] words.

Preprocessing

Figure 2 shows a roadmap for text mining process. Using common data cleaning steps, null values and outliers (e.g., making text all lower case, removing punctuation and non-sensical text) were removed. Next, using spelling corrector[27] texts were checked and corrected for spelling and then tokenized (using both phrase and word tokenizer function) into individual words.

Classification

Tokens (i.e., individual words) were classified according to the goal setting lexicon using regular expression algorithms. Unclassified words (words not found in the lexicon) were POS tagged to their corresponding part of speech. This step was to provide linguistic signal on how the words were used in the context of the goals to better verify their category in the lexicon. For all newly classified words "*lemmatizer ()*" function was used to find words' lemma (root) followed by "*synset ()*" function to find meaningful synonyms. All these words were then added to the goal setting lexicon improving accuracy of the text mining process for the next iteration.

To check the reliability of text mining results, 20% of the goals were randomly selected and manually evaluated by 5 experts in the field of rehabilitation. Manual evaluation involved

---

[1] Natural Language Toolkit

experts making their own judgment regarding the classification of words. Each expert evaluated 20 goals and were all blinded to the lexicon. Interrater reliability (between the raters and text mining classification) was tested using Cohen's Kappa.

To understand goal areas and participants' priorities, topic modeling was first tried which did not provide meaningful information. This could be due to short length of sentences and corpus volume. Instead, thematic analysis was performed to identify goal areas. Emerged themes were then mapped to the International Classification of Functioning, Disability and Health (ICF).[28] The ICF has been widely used as a coding scheme across various health and functional status by addressing biopsychosocial and environmental domains.[29] Top 10 goal areas for both groups were ranked. Distribution of ranks for the common goal areas between groups was tested using Wilcoxon rank sum test.

Statistical analysis

Descriptive statistics were used to analyze the characteristics of the participants as well as total number of goals set by each group. The second main outcome – goal specificity – was defined as the rate of specific words per person-words. Text mining process provided quantifiable data for this purpose – cumulated number of specific words and total words used by each group in their goals. Thus, the analysis aimed to compare this rate across groups. Using negative binomial regression, we estimated the rate ratio and 95% confidence intervals. Negative binomial was a more appropriate model to use due to overdispersion of our count data (count of specific words). Pearson Chi^2 dispersion statistics for the Poisson model had a ratio of 2.17 (presenting greater variability) and the negative binomial model showed a value of 1.02 for the corresponding entry.

Cognitive ability in terms of memory, information processing, or comprehension, etc. is one component that could affect goal formulation.[30] In order to see whether cognitive ability of

participants affected goal specificity, cognition was added to the model as an interaction term. Data on this variable was gathered through the BHN study. Cognitive ability was measured using a computerized test – Brief Cognitive Ability Measure (B-CAM).[31] We have used the most recent B-CAM score of the participants measured in 2020. B-CAM is a continuous variable with a total score of 36.

No gender-based analysis was done because of small count for this variable to have any meaningful information. The proportion of women in this study was ~10% (n = 6 per group). Thus, gender was not modeled in the regression equation:

Log (E(Rate of Goal Specificity)) = (groups) + (B-CAM scores) + (groups*B-CAM scores)

Correlations between goal specificity (rate of specific words/person-words – continuous variable) and participants' education and cognition were also calculated. Polyserial correlation was calculated with education (5 levels) and Pearson correlation with B-CAM (continuous). All analyses were done using SAS 9.4 software (SAS Institute Inc).

Sample size

The estimated sample size for this trial was 210 per arm based on an estimated rate ratio of 1.5 (calculated based on results a pilot study), power of 80% and response rate of 20%.[32] This sample size was calculated to provide a 95% confidence interval that excludes 1 (i.e., 1.23, 1.83). Based on the available sample of > 800 HIV+ men and women enrolled in the BHN this sample size deemed practical. However, only 350 participants confirmed their consent to enroll in further sub-studies under the BHN.

Due to the COVID-19 pandemic and closure of outpatient clinics, recruitment was temporarily shut down for nearly 4 months (March to June 2020). Recruitment restarted in July with slow

progression due to remote work and ongoing closure of some sites. Therefore, recruitment terminated by mid-August. This study received a high response rate of 60% (three times more than the initial assumption). Recalculating estimated confidence interval for the rate ratio of 1.5 and 30% loss to follow up with sample of 176 participants, provided a 95% confidence interval that excludes 1 (i.e., 1.09, 2.03).

Randomization and masking

With equal allocation ratio (1:1) participants were randomized into one of two groups, the intervention or control group, stratified based on gender. The randomization was computer generated by the study statistician using randomization.com. Given the intervention for this study was participants' personalized health profile, it was not possible to participants blinded to group assignment. To avoid bias in assessing outcomes, those collecting and analyzing the data were kept blind to group assignment.

Results

Figure 3 shows the study flow diagram. The available population who was agreeable to be enrolled in the BHN's sub-studies was 350. This sample was from four sites, two in Montreal, one in Vancouver, and one in Toronto. A total of 176 (87 English/89 French) participants were included in the trial and randomly assigned to the feedback group (n = 88) and control group (n = 88). Non-participation was due to not having access to the internet or lack of interest in the study. Of those randomized, nearly 40% (n = 66) of the participants dropped out – 17 withdrew from the study and 49 did not respond to the survey. This led to a total of 97 participants. Responses of 13 more participants were also added to the analysis because they had filled out but

not submitted the survey. This was after confirmation with participants. Thus, a total of 110 survey responses analyzed (56 in English/54 in French).

Characteristics of participants were mostly similar (i.e., <10% difference) between the two groups with the exception of comorbidities and living status. Presence of additional condition aside from HIV was more common in the feedback group (55 [80%] vs 34 [63%]) compared to the control group. Living alone was less common among the feedback group (23 [41%] vs 29 [54%]) than the control group (Table 1).

Control group responded to the survey faster than the feedback group (average of 8.3 days ± 8.3 vs 10.2 days ± 9.1). For both groups the majority of responses were received after the first reminder.

Number and characteristics of the goals

Table 2 shows characteristics of the goals. A total of 421 goals were formulated (227 in English /194 in French). Average number of goals was similar for both groups (3.7 for feedback group vs 3.9 for control group). Equal combination of outcome and behavioural goals were set by feedback group. Less than 10% of the goals were mixed goals (mix of outcomes with some intended behaviours on different topics). Also, less than 10% of the goals were unclear and could not be categorized. Control group set more behavioural goals than outcome goals (45% vs 37%) and 2% of their goals were vague and unclear.

Formulated goals were of highly important to both groups with mean goal importance of 8.5 out of 10. Perceived difficulty for the set goals were average for both feedback and control group (5.8 vs 5.3 out of 10 respectively). Feedback group's perceived self-efficacy was slightly higher than control group (7.4 vs 6.9).

Table 3 shows the top 10 goal areas defined by each group. Both groups had almost similar goal areas as shown by overlaps in 8 goal areas and little difference in rank. These 8 goal areas were consistent with 7 items on the Dashboard. More than 50% of the goals for both groups were mainly around self-care, managing diet and fitness, and cognition. Other common goal areas were mobility, sleep, handling stress, regulation of emotions, and socializing. Wilcoxon rank sum test for 8 common goal areas showed a difference in ranking of these areas between the two groups (p = 0.02). This difference in rank was related to two goal areas – socializing and mobility. Socializing was more observed in goals defined by feedback group than control group (ranked 7 vs 3.5) while mobility was mainly seen in goals set by control group (ranked 6.5 vs 4). This difference was consistent with participants' profile. Dealing with negative feeling such as depression and anxiety was reported by 54% of feedback group while mobility issues such as climbing stairs were more prevalent in control group (61%). Table 4 shows participants' data for Dashboard items. Detailed description of goal areas for each group has been provided in Supplementary table 1.

Text mining output

Total number of unique words (words remained after removing stop words) used by feedback group was 2187 compared to 2502 for the control group – a difference of 245 words. The shortest goal for both groups was formulated using one word which was only a broad definition of goal domain (e.g., diet, exercise). The longest goals set by the feedback and control group had 60 and 47 words respectively. Total number of specific words matching the goal setting lexicon was also more for the goals set by the control group (739) compared to the feedback group (642). Proportion of specific words used by both groups were ~30%. Average number of specific words/goal was similar for both groups (3.5 vs 3.1). Specific nouns and actionable verbs were

present to some extent. Goals were mainly missing "measurable" and "time-bound" words (Table 2).

Manual evaluation of 20% of the goals (100 goals) achieved a moderate degree of agreement with text mining output – Cohen's Kappa of 0.63 (95%CI 0.53, 0.73). Interrater agreement for sub-section of goals (20 goals) rated by each expert also showed a moderate degree agreement with Cohen's Kappa ranging from 0.54 to 0.72.

Goal specificity

Both crude and estimated rate ratio for goal specificity have been presented. Table 5 shows rate ratio of specific words (goal specificity) calculated using total number of words/person as the denominator. Negative binomial regression showed no difference in goal specificity among groups. Rate ratio of specific words/person-words was 0.93 (95% CI 0.78 – 1.10) showing the rate of specific words for the feedback group was almost similar (though slightly lower) than the control group. In other words, the Dashboard did not help with improving goal quality. Adding cognitive ability as an interaction term to the regression equation did not improve predictability of the model (RR = 1.13, 95% CI 0.45, 2.82). The correlation between goal specificity and education (r = 0.21, 95% CI 0.02, 0.38) and cognition (r = 0.17, 95% CI -0.01, 0.35) was weak.

Post survey assessment with the feedback group (response rate of 61%) showed degrees of non-compliance with the intervention. While all reported they had read their Dashboard, only 54% used it for goal setting. Despite variability in intervention uptake, no difference in goal specificity was observed.

Discussion

In this randomized controlled trial, feedback by means of a personalized health profile did not improve number and specificity of the goals set by HIV+ adults in Canada. While participants in the control group seemed more eager to receive their Dashboard as seen by their faster reply to the survey, not all participants in the feedback group used their Dashboard for setting goals. While variability in levels of adherence did not affect the outcome of interest in this trial, it informed of participants' low engagement with their Dashboard. The issue of "low engagement" with online or digital interventions have been previously reported particularly when no obvious benefit is perceived by the user.[33] Also, active engagement with digital feedback seems to happen when feedback is received "when needed".[34] It could be that, at the time of the study, participants did not consider dashboard information "as needed". Nonetheless, in this trial a pragmatic approach was chosen to determine whether the intervention works under the usual condition of our target group. Similar performance of both groups in terms of goal priorities highlights participants' insight of their health situation. Regardless of group assignment participants goal areas corresponded to 7 items on the Dashboard. More than 50% of participants in both groups were below the optimal level for all these 7 items.

To our knowledge, goal quality as a primary outcome of personalized feedback interventions has not been studied before particularly in the context of chronic conditions. Evidence on health-related behaviours as an intermediate outcome of goal setting is available and could be used as a proxy to put findings of this trial into context. Previous studies on communication of personalized feedback showed mixed results. Systematic reviews led by Krebs et al.[17] and Teasdale et al.[16] both showed positive, though small, effect of tailored digital feedback (in forms of reports or SMS) on improvement of some lifestyle behaviours such as physical activity and

diet modification. Contrary to these results, visual feedback (e.g., skin photography) or personalized estimates of a disease risk (e.g., cardiovascular diseases, cancer) made no difference on uptake of risk-reducing behaviours (physical activity, dietary intake, or medication adherence).[35,36] Despite contradictory findings, potential benefit of personalized feedback for shared and informed decision-making and reducing ambivalence was acknowledged.[37]

In this study, we considered Dashboard as a promising feedback tool to improve goal setting. Participants reported satisfaction with the Dashboard and perceived it as an easy and nice visual presentation of health-related quality of life. For some participants the Dashboard was a proof for their ideas on goals and some found it an inspiration to share with their partners, families or friends. Success in changing lifestyle behaviours could be explained by behaviour change theories such as COM-B model of behaviour change which explains that implementation or improvement of any given behaviour is informed by individual's capability, opportunity, and motivation.[38] The Dashboard has the potential to provide a quick visual understanding of one's potential capability or motivation. Items on the Dashboard are fundamental factors influencing health-related quality of life[39,40] and could primarily be modified by non-pharmacological management including self-management. Goal setting plays a dominant role in self-management interventions by laying a roadmap pointing where one stands and where they are heading.[41] The Dashboard provides the basics of goal setting by providing a reference point with having patients' visit data. Offering optimal range on the Dashboard gives a choice to the individual to decide whether they want to make a change. Having a choice is empowering and allows the person feels they are in control of their decisions and have the ability to switch between their options.[42,43]

This study has a number of strengths and limitations. The main strength of this trial is its new methodological approach for measuring goal quality. Techniques of text mining extracted useful and meaningful information from unstructured goal data in a shorter period of time and informed goal criteria. It also helped with expansion of goal setting lexicon by identification of unclassified words. The initial goal setting lexicon contained 694 words representing four goal criteria. At the end of the trial our lexicon was expanded to 994 words. Even though we did not use topic detection for identification of goal domains, text tokens alone were informative of participants' most common health-related concerns. Word cloud for French and English goals are provided in supplementary materials. Finally, while goal setting lexicon has been tested and expanded with HIV population, it is relevant to other chronic health conditions. Text mining output of this trial as well as goal setting lexicon could be useful for the future trials using text mining as an inexpensive way for evaluation of voluminous patient-defined textual data. The trial had high retention rate and the randomized controlled design supports the strength of the findings. Populations in the two groups were similar. Contamination was not an issue due to personalized nature of the Dashboard.

One limitation of this trial is its low sample size. Recruitment of participants for this trial was dependent on HIV clinics. As explained earlier, closure of HIV clinics due to COVID-19 pandemic interfered with recruitment. A bigger sample size would have helped with precision of text mining algorithms and further expansion of the goal setting lexicon, although change in the main outcome remains unlikely on the basis of low participation. . Another limitation concerns complexities of natural languages. Classification of words for different goal criteria was based on the guideline defined by our research team. Other researchers or language experts might disagree, particularly with classification of some "nouns" and "verbs" and get different results

for goal specificity. Evaluation of text data is based primarily on human judgment and is not exempt of measurement errors. As shown in our trial, manual evaluation of goals by different raters provided different agreement estimates. Raters or guidelines are not considered as reference standard[44]; yet a consensus-based application orientated guidelines – as the case in our trial – lead to a uniform approach and evaluation of data. Goal setting literature shows various interpretations of what constitutes a *good quality* goal. The use of specific, action-oriented, measurable, and time-bound criteria was for measurement purposes (using text mining) and does not indicate goals only including these criteria of higher quality than other types of goals. Goal criteria are to increase task performance and as long as there is enough information in the formulated goal to answer the above-mentioned questions, the goal is a *good* goal.

To conclude, based on our findings there is a necessity to scale up feedback tools such as personalized health profile to help with *SMART* goal setting. Text mining has the potential to help with difficulties of goal setting outside of the face-to-face setting. Obviously, a larger patient formulated goal data would be needed to provide a real-life information on what words are commonly being used and what goal criteria are missing. This would lead to a unique and valuable dataset of its kind. As data grows larger, with the use of learning models automated answers could be generated to provide a more dynamic platform. Future comparative studies could highlight the strengths and weaknesses of text mining approach for both goal evaluation and goal setting.

Supplementary material

- Supplementary Table 1: Goal areas mapped to the ICF, frequencies, and illustrative quotes for each ICF code

- Supplementary Figure 1-4: Word clouds for English and French goals set by Dashbaord and control group. Word clouds were generated with de-identified trial data using Voyant Tools – a web-based text reading and analysis environment.[45]

- Reporting guidline: CONSORT checklist fo rpragmatic trials

Extended data

Open Science Framework: Goal Setting in HIV, https://doi. org/10.17605/OSF.IO/FW4SX35.

This project contains the following extended data:

- Goal evaluation guideline for text mining

- Informed consent form for participants

- Initial start-up lexicon – version 1 (English and French)

- Expanded lexicon – version 2 ((English and French)

Reference:

1.   Dowrick C, Dixon-Woods M, Holman H, Weinman J. What is chronic illness? *Chronic Illn.* 2005;1(1):1-6.

2.   Grady PA, Gough LL. Self-management: a comprehensive approach to management of chronic conditions. *Am J Public Health.* 2014;104(8):e25–e31.

3.   Hessler DM, Fisher L, Bowyer V, et al. Self-management support for chronic disease in primary care: frequency of patient self-management problems and patient reported priorities, and alignment with ultimate behavior goal selection. *BMC Fam Pract.* 2019;20(1):120.

4.   Public Health Agency of Canada. *Population-specific HIV/AIDS status report: People living with HIV/AIDS.* 2013.

5.   Deeks SG, Lewin SR, Havlir DV. The end of AIDS: HIV infection as a chronic disease. *Lancet.* 2013;382(9903):1525–1533.

6.   World Health Organization. HIV: From a devastating epidemic to a manageable chronic disease. In: *Ten years in public health, 2007–2017: Report by Dr Margaret Chan, Director-General, World Health Organization.* Geneva: World Health Organization, Licence: CC BY-NC-SA 3.0 IGO.; 2017.

7.   Safreed-Harmon K, Anderson J, Azzopardi-Muscat N, et al. Reorienting health systems to care for people with HIV beyond viral suppression. *Lancet HIV.* 2019;6(12):e869-e877.

8.   Lorig KR, Holman H. Self-management education: History, definition, outcomes, and mechanisms. *Ann Behav Med.* 2003;26(1):1-7.

9.	Kuo CC, Wang RH. Appraisal of the application of empowerment elements and strategies: The example of chronic metabolic diseases. *Chung-Hua Hu Li Tsa Chih (Chinese Journal of Nursing)*. 2013;60(1):78-86.

10.	Vermunt N, Harmsen M, Westert GP, Olde Rikkert MGM, Faber MJ. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: A systematic review. *BMC geriatr*. 2017;17(1):167.

11.	Mozafarinia M, Brouillette M, Fellows L, Knäuper B, Mayo N. An umbrella review of the literature on the effectiveness of goal setting interventions in improving health outcomes in chronic conditions. In. [Manuscript in preparation]2020.

12.	Salter C, Shiner A, Lenaghan E, et al. Setting goals with patients living with multimorbidity: qualitative analysis of general practice consultations. *Br J Gen Pract*. 2019;69(684):e479-e488.

13.	Tai-Seale M, McGuire TG, Zhang W. Time allocation in primary care office visits. *Health Serv Res*. 2007;42(5):1871-1894.

14.	Davis S, Abidi SS, Stewart S. A compositional personalization approach for designing personalized patient educational interventions for cardiovascular risk management. *Stud Health Technol Inform*. 2010;160(Pt 1):629-633.

15.	Dineen-Griffin S, Garcia-Cardenas V, Williams K, Benrimoj SI. Helping patients help themselves: A systematic review of self-management support strategies in primary health care practice. *PLoS ONE*. 2019;14(8):e0220116.

16.   Teasdale N, Elhussein A, Butcher F, et al. Systematic review and meta-analysis of remotely delivered interventions using self-monitoring or tailored feedback to change dietary behavior. *The Amn J Clin nutr.* 2018;107(2):247-256.

17.   Krebs P, Prochaska JO, Rossi JS. A meta-analysis of computer-tailored interventions for health behavior change. *Prev Med.* 2010;51(3):214-221.

18.   Kreuter MW, Wray RJ. Tailored and Targeted Health Communication: Strategies for Enhancing Information Relevance. *Am J Health Behav.* 2003;27(1):227-232.

19.   Mozafarinia M, Rajabiyazdi F, Brouillette M, Fellows L, Knäuper B, Mayo N. 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]. *MNI Open Res.* 2020;4(1).

20.   Zwarenstein M, Treweek S, Gagnier JJ, et al. Improving the reporting of pragmatic trials: an extension of the CONSORT statement. *BMJ.* 2008;337:a2390.

21.   Mayo NE, Brouillette MJ, Fellows LK, Positive Brain Health Now Investigators. Understanding and optimizing brain health in HIV now: Protocol for a longitudinal cohort study with multiple randomized controlled trials. *BMC neurol.* 2016;16(8).

22.   Mozafarinia M, Rajabiyazdi F, Brouillette MJ, Fellows LK, Knäuper B, NE. M. Goal Setting in HIV. osf.io/exujm. Published 2020. Accessed.

23.   Mozafarinia M, Rajabiyazdi F, Brouillette M-J, Fellows LK, Mayo NE. Development and usability of a feedback tool, "My Personal Brain Health Dashboard", to improve setting of self-management goals among people living with HIV in Canada. *Qual Life Res.* 2020.

24.   Doran GT. There's a S.M.A.R.T. Way to Write Management's Goals and Objectives. *Manag Rev.* 1981;70:35-36.

25.   Christiane F. WordNet: An Electronic Lexical Database. In. MIT Press1998.

26.   Sagot B, Fišer D. Building a free French wordnet from multilingual resources. In. *Ontolex*. Marrakech, Maroc 2008.

27.   *Spelling Corrector in Python 3* [computer program]. MIT license: www.opensource.org/licenses/mit-license.phpCopyright (c) 2007-2016.

28.   World Health Organization. International classification of functioning, disability and health: ICF. In: Geneva: World Health Organization; 2001: https://apps.who.int/iris/handle/10665/42407.

29.   Centers for Disease Control and Prevention. The ICF: an overview. https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf. Accessed Feb 12, 2021.

30.   Schouten J, Cinque P, Gisslen M, Reiss P, Portegies P. HIV-1 infection and cognitive impairment in the cART era: a review. *AIDS (London, England).* 2011;25(5):561-575.

31.   Brouillette MJ, Fellows LK, Palladini L, Finch L, Thomas R, Mayo NE. Quantifying cognition at the bedside: a novel approach combining cognitive symptoms and signs in HIV. *BMC Neurol.* 2015;15(1):224.

32.   Wengrzik J, Bosnjak M, Lozar Manfreda K. Web surveys versus other survey modes: An updated meta-analysis comparing response rates. Paper presented at: General Online Research Conference 2016; Dresden, Germany.

33. Davies EL, Khajesari Z, Perski O, Garnett C. Finding moderation online: digital interventions to reduce alcohol consumption. *Psychologist.* 2019;32:44-47.

34. Eysenbach G. The Law of Attrition *J Med Internet Res.* 2005;7(1):e11.

35. Usher-Smith JA, Silarova B, Sharp SJ, Mills K, Griffin SJ. Effect of interventions incorporating personalised cancer risk information on intentions and behaviour: a systematic review and meta-analysis of randomised controlled trials. *BMJ Open.* 2018;8(1):e017717.

36. Hollands GJ, French DP, Griffin SJ, et al. The impact of communicating genetic risks of disease on risk-reducing health behaviour: systematic review with meta-analysis. *BMJ.* 2016;352:i1102.

37. Edwards AGK, Naik G, Ahmed H, et al. Personalised risk communication for informed decision making about taking screening tests. *Cochrane Database Syst Rev.* 2013(2).

38. Michie S, Atkins L, West R. *The behaviour change wheel: A guide to designing interventions.* Great Britain: Silverback Publishing; 2014.

39. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA.* 1995;273(1):59-65.

40. Rosenzveig A, Kuspinar A, Daskalopoulou SS, Mayo NE. Toward patient-centered care: a systematic review of how to ask questions that matter to patients. *Medicine (Baltimore).* 2014;93(22):e120.

41. Gardner T, Refshauge K, McAuley J, Goodall S, Hubscher M, Smith L. Patient-led goal setting. *Spine.* 2016;41(18):1405-1413.

42. Gardner B, Lally P, Wardle J. Making health habitual: the psychology of 'habit-formation' and general practice. *Br J Gen Pract.* 2012;62(605):664-666.

43. Sadler E, Wolfe CDA, Jones F, McKevitt C. Exploring stroke survivors' and physiotherapists' views of self-management after stroke: A qualitative study in the UK. *BMJ Open.* 2017;7(e011631).

44. Hutchings A, Raine R, Sanderson C, Black N. A comparison of formal consensus methods used for developing clinical guidelines. *J Health Serv Res & Policy.* 2006;11(4):218-224.

45. Sinclair S, Geoffrey R. Voyant Tools. Web. http://voyant-tools.org/. Published 2016. Accessed January 2021.

Your Personal Brain Health Profile

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 a computer test 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 or close your values were compared to the optimal values. You can find the colors codes at the bottom of the Dashboard.

You might find that your status for some of the items on the Dashboard have 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:

	Items on your Dashboard	How they were measured?
1	Cognitive test score	This was evaluated by a computer test.
2	Your evaluation of your memory	You filled out a questionnaire and answered questions about your memory status.
3	Able to concentrate	You were asked to think about the last 2 weeks and answer how well are you able to concentrate.
4	Negative feelings (blue mood, despair, anxiety, depression)	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.
5	Feeling lonely	You were asked whether or not you find yourself feeling lonely.
6	Time feeling worn out	You were asked to think about the last 4 weeks and answer how much of the time did you feel worn out.
7	Feeling rested after waking up	You filled out a questionnaire with focus on your sleep status.
8	Your pain rating	You were asked to think about the last 4 weeks and answer how much bodily pain did you have.
9	Climbing several stairs	You were asked how much you find yourself limited in climbing several stairs.
10	Walking more than a kilometer	You were asked how much you find yourself limited in walking more than a kilometer.
11	Vigorous activities	You were asked how much you find yourself limited in doing vigorous activities.
12	Weight to height ration (BMI)	We measured your weight and your height, and this value shows whether your weight in proportion to your height is healthy or not.
13	Smoking	You were sked if you are a current smoker.
14	Health rating	You were asked, in general how would you say your health is?
15	Quality of life	You were asked how you would rate your quality of life?

See next page for your "Personal Brain Health Dashboard"

Figure 1A Dashboard

BRAIN HEALTH NOW : Your Personal Brain Health Profile

Participant Number:10-005			
Important Brain Health Areas	**Your first visit**	**Your most recent visit**	**Optimal**
Visit date	February 27, 2014	July 18, 2017	
Cognitive test score	Good	Excellent	**Excellent**
Your evaluation of your memory	Good	Excellent	**Excellent**
Able to concentrate	A moderate amount	A moderate amount	**Very much to extreme**
Negative feelings (blue mood, despair, anxiety, depression)	Very often	Always	**Never or seldom**
Feeling lonely	Sometimes	Almost never	**Almost never**
Time feeling worn out	A Good Bit	A Good Bit	**None to a little**
Feeling rested after waking up	Never	Never	**Often or always**
Your pain rating	Moderate	Very Severe	**None to mild**
Climbing several stairs	Not limited	Limited a lot	**Not limited**
Walking more than a kilometer	Not limited	Limited a lot	**Not limited**
Vigorous activities	Limited a little	Limited a lot	**Not limited**
Weight to height ratio (BMI)	24	26	**Between 19 and 25**
Smoking	Not smoking	Not smoking	**Not smoking**
Health rating	Good	Fair	**Excellent, very good**
Quality of life	Neither poor or good	Poor	**Good, very good**

☐ The green boxes indicate areas where you are in the optimal state
☐ The neutral boxes 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 = 3
Number of optimal areas at my most recent visit = 3

Figure 1B Dashboard
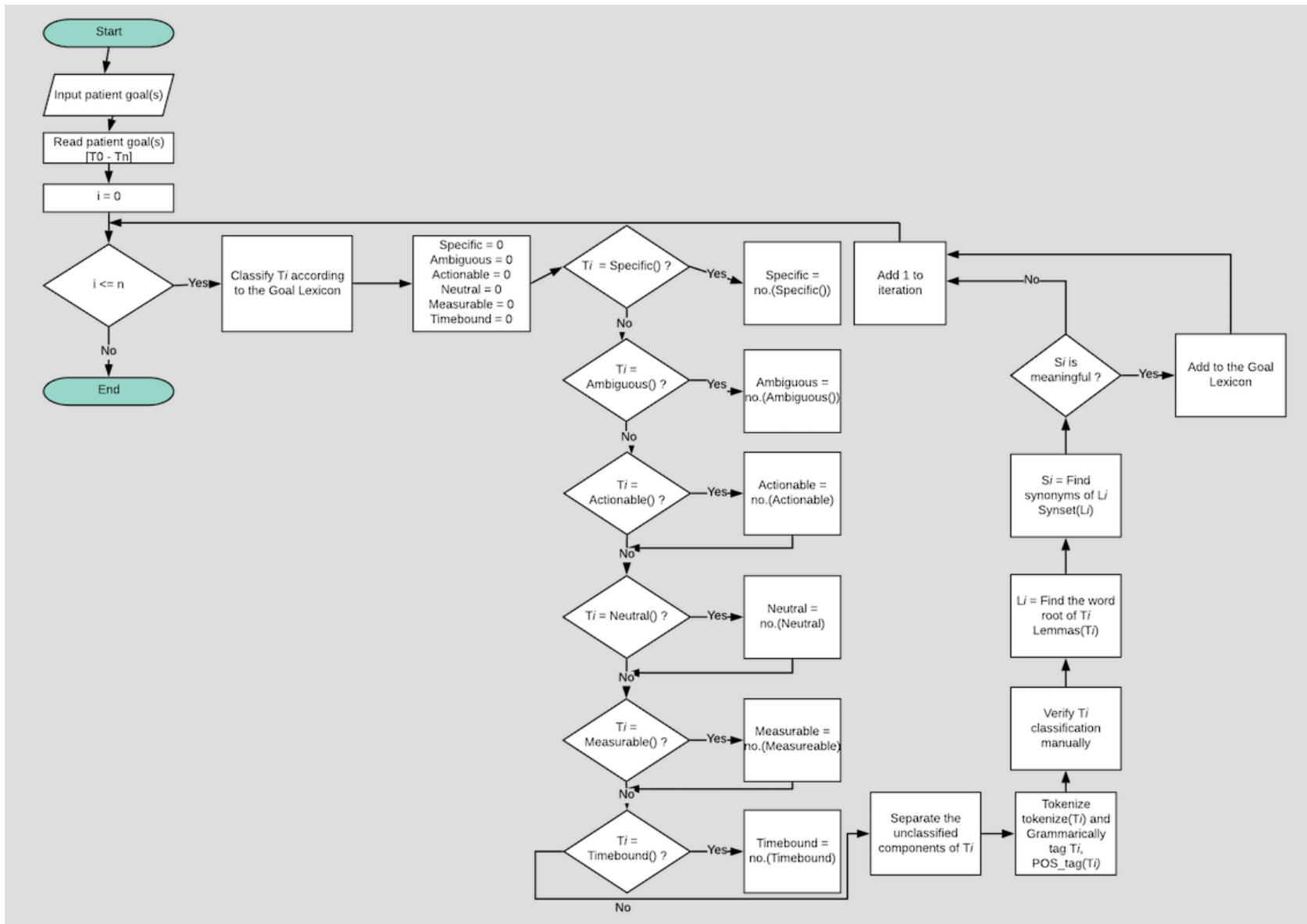
Figure 2 Text mining flowchart
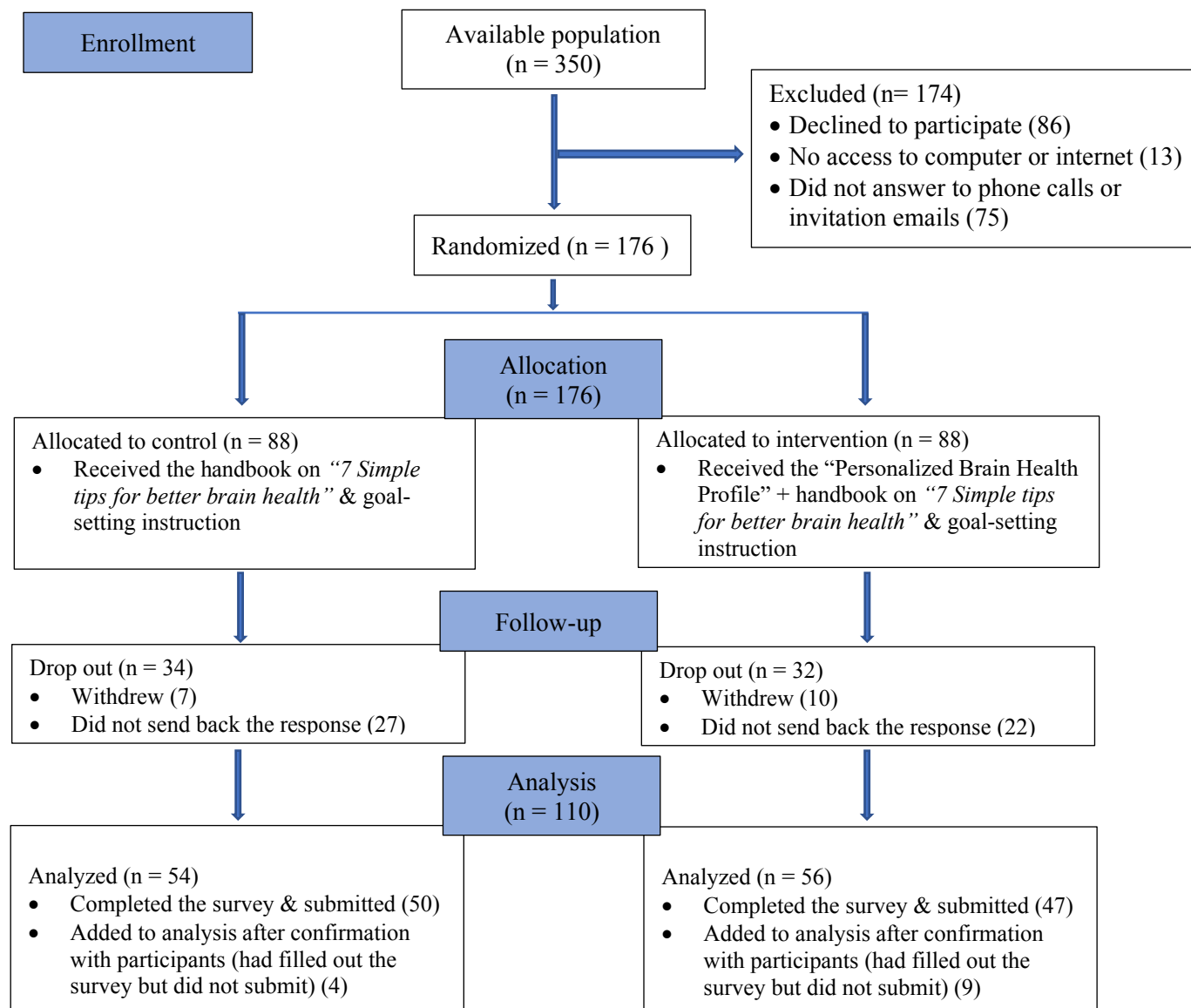
Figure 3 Flow diagram for "goal setting in HIV" trial
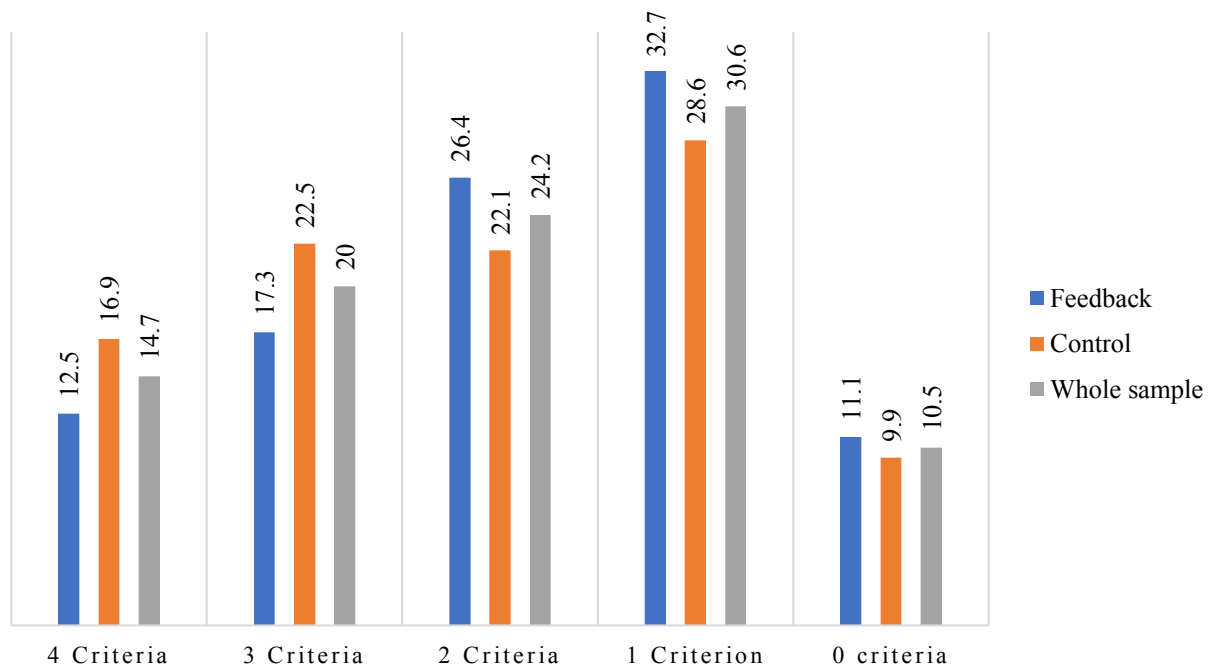
Figure 4 Proportion of *SMART* criteria –as per text mining output – per group and for the whole sample. Criteria includes 'specific noun, actionable verb, words representing 'metrics', and 'time'.

Table 1 Characteristics of the participants

	Feedback group No. (%)	Control group No. (%)
Number	56	54
Age (mean ± SD)	58.21 ± 7.6	59.99 ± 7.8
Women	6 (10.7)	6 (11.1)
Men	50 (98.3)	48 (88.9)
Education		
< College	15 (26.7)	14 (25.9)
College	19 (33.9)	17 (31.5)
Undergraduate	9 (16.1)	14 (25.9)
Graduate	12 (21.4)	9 (16.7)
Years of living with HIV (mean ± SD)	21.5 ± 7.8	22.8 ± 7.4
CD4 (mean ± SD)	618 ± 271	609 ± 218
Nadir CD4 (mean ± SD)	187 ± 151	213 ± 131.5
Comorbidity		
0	11 (19.6)	20 (37.1)
1	19 (33.9)	12 (22.2)
2	10 (17.9)	10 (18.5)
>2	16 (28.6)	12 (22.2)
Living status		
Alone	23 (41.1)	29 (53.7)
Working status		
Working > 15 h/w	24 (42.9)	21 (38.9)
Cognitive status (0-36)* **(as presented on the Dashboard)**		
Excellent	24 (42.8)	22 (40.7)
Good	15 (26.8)	15 (27.8)
Fair	17 (30.4)	17 (31.5)

*Cognitive status was measured with B-CAM, a performance-based measure of cognitive ability based on domains of executive function, memory, attention and language. Higher score represents a better cognitive ability. Scores were categorized to be presented on the Dashboard.

Table 2 Characteristics of the goals

	Feedback group No. (%)	Control group No. (%)
Total # of goals (mean)	208 (3.7)	213 (3.9)
Outcome goals	89 (42.8)	80 (37.6)
Behavioural goals	88 (42.3)	96 (45.1)
Mixed	16 (7.7)	32 (15.0)
unclear	15 (7.2)	5 (2.3)
Mean goal importance	8.5	8.5
Mean goal difficulty	5.8	5.3
Mean self-efficacy	7.4	6.9
Total # of unique words[*]	2187	2502
Total # specific words	642 (29.3)	739 (29.5)
Specific nouns	236 (36.8)	256 (34.6)
Actionable verbs	250 (38.9)	259 (35.0)
Units of measure	63 (9.8)	89 (12.0)
Timebound	93 (14.5)	129 (17.5)
Crude rate of specific words/person's unique words	21.1	19.1
Crude rate ratio of specific words/person's unique words*	1.1	

*Unique words = Words after removing stop-word

Table 3 Top 10 goal areas and shared goal areas between groups

Control group			Goal area		Feedback group		
%	N	Rank			Rank	N	%
27.8	52	10	Looking after one's health	Looking after one's health	10	56	28.1
13.4	25	9	Managing diet and fitness	Managing diet and fitness	9	33	16.6
7.5	14	8	Cognition (higher level of cognition & memory)	Cognition (higher level of cognition & memory)	8	15	7.5
6.9	13	6.5	Mobility (moving around, walking, climbing up the stairs)	Socializing	7	13	6.5
6.9	13	6.5	Sleep	Sleep	5.5	11	5.5
4.8	9	5	Handling stress (anxiety)	Handling stress (anxiety)	5.5	11	5.5
4.3	8	3.5	Regulation of emotions	Mobility (moving around, walking, climbing up the stairs)	4	10	5.0
4.3	8	3.5	Socializing	Family relationship	3	6	3.0
3.7	7	2	Recreation & leisure	Regulation of emotions	1.5	5	2.5
2.1	4	1	Generalized pain	Confidence	1.5	5	2.5
81.7	153		Total			165	82.7

Wilcoxon rank sum test				
	N. of common goals areas	Sum of observations	Mean rank	Sum of ranks
Feedback group	8	154	8.5	68
Control group	8	142	7.8	63
Std. Error		11.66		
Z Stat		2.27		
P Value (two-sided)		0.02		

Goal areas shaded in grey are shared areas between both groups. Colors show the ranks for each goal area.

Table 4 Proportion of participants below the optimal level on Dashboard items

Dashboard items	Dashboard group (N=54) n (%)	Control group (N=56) N (%)
Cognition	31 (57.4)	29 (56.8)
Memory	**25 (45.4)**	**29 (55.8)**
Concentration	28 (50.0)	24 (44.4)
Negative feelings (depression, anxiety, despair, blue mood)	**30 (53.6)**	**21 (38.9)**
Feeling lonely	34 (60.7)	28 (51.8)
Feeling worn out	32 (57.2)	33 (61.1)
Feeling rested after waking up	19 (34)	15 (27.8)
Pain	16 (28.6)	15 (27.8)
Climbing several stairs	**18 (32.1)**	**33 (61.1)**
Walking more than a kilometer	18 (32.1)	17 (31.5)
Vigorous activities	37 (66.1)	41 (76.0)
Weight to Height ratio (BMI)	**26 (46.5)**	**31 (58.4)**
Smoking	8 (15.7)	10 (19.2)
Health rating	30 (53.6)	28 (52.8)
Quality of life	**12 (21.4)**	**17 (31.5)**

Items with >10% difference are shown in bold.

Table 5

A: Negative binomial regression analysis on number of specific words for feedback and control groups with and without an interaction term

Specific words (Response variable)	Coef.	Std.Err	ChiSq	ProbChiSq	95% conf. Interval	
Intercept	0.36	0.35	1.08	0.29	-0.32	1.04
Group (feedback)	0.12	0.47	0.06	0.80	-0.80	1.04
B_CAM	0.01	0.005	3.18	0.07	-0.001	0.02
B_CAM*group	-0.003	0.007	0.15	0.70	-0.01	0.01
Dispersion	0.11	0.03	–	–	0.06	0.18
Rate ratio of specific words per person's words						
	Feedback group			Control group		
RR (95% CI) without interaction term						
	0.93 (0.78 – 1.10)			Referent		
Rate ratio, RR (95% CI) with B_CAM as an interaction term						
	1.13 (0.45 – 2.82)			Referent		

B: Correlation between specific words/person words and B_CAM and education

	Specific words/person words			
	N	r	95% conf. Interval	P
Education (categorical)	109	0.21	0.02 – 0.38	0.04
B_CAM (continuous)	110	0.17	-0.01 – 0.35	0.07

Note: Polyserial correlation has been calculated with education classified in 5 levels. Pearson correlation has been calculated with cognitive ability (measured using a computerized test – B_CAM).

Supplementary Table 1 Goal areas mapped to the ICF, frequencies (per group), and illustrative quotes for each ICF code

Participants reported goal areas mapped to the ICF		Feedback		Control		Example quote
		No.	(%)	No.	(%)	
Temperament and personality, Energy and drive	b1265 optimism	1	0.50	3	1.60	Widower for a bit more than 1 year & hard to move on sometimes but must. Be happy go lucky.
	b126 temperament and personality	5	2.51	2	1.07	I want to improve my overall mood. To be a calmer, friendlier and more engaging person
	b1266 confidence	2	1.01	1	0.53	Avoir plus confiance en moi.
	b1301 motivation	1	0.50	–	–	Turn errands/chores into pleasure
	b1303 craving substances (that can be abused)	–	–	1	0.53	I will conquer my substance use problem by this summer through continuing to get professional care and taking anti-craving mess and, most important, by ending friendships and sexual relationships with substance users.
	b134 sleep function	11	5.53	13	6.95	Sleep 7 hours a night on a regular basis.
	b140 attention functions	2	1.01	–	–	Me concentrer dans mes projets.
	b144 memory function	3	1.51	**6**	3.21	I will improve my mental health throughout this time of self-isolation. I have a habit of watching tv and movies when I am at home and I can feel my memory is not as sharp as it used to be. Alzheimer's and Dementia also run in my family, so I want to strengthen my brain health. I will read one book per week from now until July and if I find an online course, I will sign up for it.

	b1521 regulation of emotions	5	2.51	8	4.28	Faire la paix avec le décès de ma mère
	b164 higher-level cognitive function	12	6.03	8	4.28	I want to challenge my mind and keep it sharp. Although I do a lot of reading at home, my plan would be to join the local book club (once a month), do crossword puzzles (buy a book of crossword puzzles to complete one daily, and spend more time at the library.
	b1642 time management	–	–	1	0.53	Manage my time better.
Sensory function & pain	b2400 tinnitus	–	–	1	0.53	My tinnitus as result of a workplace injury is off the charts. I will enroll in the Tinnitus Retraining Therapy course offered by the past President of the Canadian Hearing Society within the next month (pending financial capabilities as it's not covered by OHIP), in an effort to reduce the level of tinnitus and learn how to focus on other things. I want to do this to reduce frustration, reduce my constant fatigue due to waking up several times each night as a result of the ringing, and to get back to work full-time at full capacity. I will do this by committing to the course therapies on a daily basis.
	b2800 generalized pain	4	2.01	4	2.14	I want to lose 20 lbs. in the next 20 weeks. I want to do this so the pain in my lower back become less severe and I can breathe and sleep better. I will do this by doing cardio at the gym 4 times a week for 30-40 minutes.
Respiration function	b440 respiration function	1	0.5	–	–	Mieux respirer.

	b455 Exercise tolerance function (climbing stairs)	–	–	1	0.53	I will be improving my endurance within 3 months from today. I want to do this so that I am able to climb the stairs in my home without being so winded. I will do this by doing moderate endurance training exercises at the gym 2 times per week.
Movement function	b770 gait pattern function	1	0.5	–	–	J'améliorerai ma mobilité d'ici 2 mois suite à une intervention chirurgicale - remplacement du genou droit.
Learning	d1551 acquiring complex skills	1	0.5	1	0.53	Learn to be proficient at a new skill like "Sketchup".
General tasks and demands	d2401 handling stress	11	5.53	9	4.81	Gérer le stress en faisant des respirations profondes 3 fois par jour.
Walking & moving	d450 walking	6	3.02	1	0.53	Santé physique. Toujours par le programme de cardiologie préventive (CHUM), on me propose de marcher de 20 à 30 minutes au moins cinq (5) fois par semaine. Objectif; au fois 5 fois, par semaine, je sors pour une marche de 30 minutes.
	d455 moving around	4	2.01	11	5.88	Faire du vélo 3 heures par semaine.
	d4554 swimming	1	0.50	–	–	Recommencer la natation.
Self-care	d520 caring of the body part	1	0.50	1	0.53	Deal with my problems with my skin in the next 3 months. As I have had cancer and my family is prone to skin cancer. I want to have this checked out by a dermatologist, so I know where I stand with this issue. Because of the Covid-19 pandemic I have had to cancel an appointment but hope to make new one in a couple of months.
	d540 dressing	1	0.50	–	–	Pouvoir porter mes vêtements

	d570 looking after one's health	56	28.14	52	27.81	I would like to work towards become as active as I was in the past years. With a new job and commitments that I have made to it, I often find it difficult to be active after a very long day. I would like to create a daily routine that works for my busy lifestyle.
	d5701 managing diet and fitness	33	16.58	25	13.37	I will lose 35lb by June of this year through increased exercise and better diet.
	d599 self-care unspecified	–	–	2	1.07	Good health
Domestic life	d610 acquiring a place to live	1	0.50	1	0.53	I presently reside in a government subsidized apartment in a building which is not very well maintained, and because of bad air quality, it is very harmful to my health, i would like to eventually move to a much to a building with a cleaner and healthier environment.
	d630 preparing meals	–	–	1	0.53	Cook more food myself, not just leave it to my partner to do.
	d6402 cleaning living area	3	1.51	–	–	Je veux faire du ménage de mes garde-robes afin de me défaire des choses qui encombrent ma demeure. Je vais me demander si c'est encore utile, pratique ou être donner à d'autres qui en auraient besoin ou utile à eux. Je vais faire cela un peu tous les jours afin que ce projet soit terminé pour la fin du mois avril 2020.
	d650 caring for household	–	–	2	1.07	I would like to do renovations in my apartment in the next 6 months.
	d660 assisting others	1	0.50	–	–	Caring for my children

171

Interpersonal interactions and relationships	d7200 forming relationships	–	–	2	1.07	My goal is to make new friends.
	d7201 terminating relationship	–	–	1	0.53	I want to ensure I have a completed divorce from my past partner in the next two months, so I can then have more options about who & how I choose to share my life. I have already sourced that my ex has passed away so I will be following up with family for a certificate of death to ensure closure.
	d760 family relationship	6	3.02	3	1.60	To visit family and friends and family and friends who all live in Ontario more often. I'm not very close to a good number of family members, but I do miss the ones with whom I'm closer to and i am afraid of aging and being alone.
	d770 intimate relationships	–	–	3	1.60	Trouver éventuellement un partenaire sexuel compatible pour combler mes besoins dans ce sens.
	d820 school education	1	0.50	–	–	Retourner à des études
Major life areas	d840 work preparation	–	–	1	0.53	To improve myself and qualify for market employment so as to get out of the ODSP by the next 2 years
	d8450 seeking employment	–	–	2	1.07	I will find a job and make money, in the next 6 months so I can feel more productive and be able to pay off my debts and go on vacations.
	d8500 self-employment	1	0.50	–	–	Mettre en pratique l'ensemble de mes expériences acquises pour m'auto gérer sans pression.
	d859 work & employment	1	0.50	–	–	Organiser et terminer à temps toutes les tâches administratives concernant ma vie professionnelle et personnelle (impôts, comptes, appel téléphonique, administration du condo,

						véhicule...etc.…etc.…) avant un départ pour 6 mois.
	d860 basic economic transactions	1	0.50	1	0.53	Take better care of my financial affairs to get rid of a lot of stress to develop a budget which I have never done before, be more responsible in spending frivolously and to try and save more.
	d870 economic self-sufficiency	–	–	2	1.07	I would like to work on financial planning.
	d879 economic life	5	2.51	1	0.53	My goal would be to become completely independent with regards to my living situation. Have a good paying job where I can afford to live on my own and save money.
Community, social, & civic life	d910 community life	–	–	1	0.53	To expand my social welfare by at least engaging in a social group once a month for the next 12 months by attending biweekly meetings.
	d920 recreation and leisure	3	1.51	**7**	3.74	Devote more time to reading for pleasure.
	d9205 socializing	13	6.53	8	4.28	I want to entertain friends at home at least six times in the next year. I want to do this so that I can maintain friendships and offer something back for people who invite me over often. I will do this by setting up a calendar of likely dates, sending invitations out early, and maintaining a file of menu possibilities.
	d9301 spirituality	1	0.50	–	–	Spiritual connection with My God and savior Jesus His son
Total		199		187		

*This code was chosen as the enabler mentioned for this goal was to take a leave of absence to have more time to take care of the children.
**ODSP: Ontario Disability Support Program
Out of 421 goals, 35 were either unclear or could not be mapped under ICF domains.

Supplementary Figure 1 Word cloud for English goals set by Dashbaord group

This word cloud was generated with de-identified trial data using Voyant Tools – a web-based text reading and analysis environment. Sinclair, Stéfan and Geoffrey Rockwell, 2016. *Voyant Tools*. Web. http://voyant-tools.org/.

Supplementary Figure 2 Word cloud for French goals set by Dashbaord group

This word cloud was generated with de-identified trial data using Voyant Tools – a web-based text reading and analysis environment. Sinclair, Stéfan and Geoffrey Rockwell, 2016. *Voyant Tools*. Web. http://voyant-tools.org/.

Supplementary Figure 3 Word cloud for English goals set by control group

This word cloud was generated with de-identified trial data using Voyant Tools – a web-based text reading and analysis environment. Sinclair, Stéfan and Geoffrey Rockwell, 2016. *Voyant Tools*. Web. http://voyant-tools.org/.

Supplementary Figure 4 Word cloud for French goals set by control group

This word cloud was generated with de-identified trial data using Voyant Tools – a web-based text reading and analysis environment. Sinclair, Stéfan and Geoffrey Rockwell, 2016. *Voyant Tools*. Web. http://voyant-tools.org/.

CHAPTER 10: Integration of Manuscripts IV & V

Research Objectives of Manuscript IV

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.

Research Objectives of Manuscript V

To identify the perceived barriers and enablers to acting on self-management goals among people living with HIV in Canada.

Integration of Manuscript IV and V

The fourth manuscript suggested similar goal setting capability among individuals in both feedback and control groups. In addition, insightful information regarding goal areas and their priorities was observed. To tackle self-management readiness, it is important to understand influences of self-management goals judged by the persons living the condition. The goal of manuscript V – a qualitative secondary analysis – was to identify the perceived barriers and enablers of self-management goals defined by people living with HIV.

CHAPTER 11 : Manuscript V

Barriers and Enablers to Acting on Self-Management Goals among People Living with

HIV in Canada

Maryam Mozafarinia*[1,6], Marie-Josée Brouillette[2,6], Lesley K. Fellows[3], Bärbel Knäuper[4], and

Nancy E. Mayo[1,5,6]

[1]Division of Experimental Medicine, [2]Department of Psychiatry, [3]Department of Neurology and

Neurosurgery and Chronic Viral Illness service, [4]Department of Psychology, [5]Department of

Medicine and School of Physical and Occupational Therapy,

[6]Center for Outcome research & Evaluation,

McGill University, Montreal, Canada

Correspondence author:

Maryam Mozafarinia, RN, BScN, MScN,
Division of Experimental Medicine, Faculty of Medicine, McGill University &
Center for Outcome Research and Evaluation (CORE)
McGill University Health Centre Research Institute
5252 de Maisonneuve, Office 2C:13
Montréal, Québec, H4A 3S5
E-mail: maryam.mozafarinia@mail.mcgill.ca

Abstract

People living with chronic HIV are dealing with many parallel but often competing self-management needs. This study aimed to identify barriers and enablers to self-management goals among HIV+ older adults in Canada. Using data from "*Goal setting in HIV*" project, 110 survey responses were thematically analyzed. Barriers and enablers were categorized to the components of Capability, Opportunity, Motivation, and Behaviour (COM-B) model of behaviour. Health as a general concept and managing diet and fitness were the most common self-management priorities. Difficulty breaking down routines and habits and lack of time and motivation formed majority of perceived barriers. Perceived enablers were mainly focused on improving psychological capability (establishing better habits) and physical opportunity (time management, financial plans, and seeking treatment). HIV+ people are able to report their priorities, areas of challenges, and potential facilitators. Enabling HIV population to translate these self-management ideas into practice is of paramount importance.

Keywords: Self-management, Behaviour change, Self-care, Chronic HIV, COM-B model

1. INTRODUCTION

There has been much advancement in the HIV care continuum since the introduction of combination antiretroviral therapy (cART). Remarkable success of the medication in adequately suppressing the virus replication has transformed HIV into a chronic, manageable medical condition.[1] Now, people with HIV are living a longer life as long as medication continued to be taken.[2] Ageing with HIV, however, has raised an important question that "how well people with HIV are living and ageing?" Lower health-related quality of life (HRQoL) due to complex health and social challenges associated with ageing, HIV-positive status, and co-occurring physical and psychological conditions has been consistently reported in the literature.[3,4] The HIV field is now beginning to embrace a comprehensive orientation to HIV care by adding the "fourth 90" – addressing HRQoL of People with HIV – to the global 90-90-90 percent targets of HIV diagnosis, treatment, and viral suppression.[5,6]

Self-management (sometimes also referred as self-care) is a key factor in the chronic disease management model.[7,8] The idea underpinning self-management is that people who are living a chronic condition can be helped to "acquire skills, strategies, and knowledge to manage the physical, psychological, emotional, and social effects of a chronic condition".[9,10] Self-care holds a related but distinct definition by acknowledgement of individuals social network. According to the World Health Organization, self-care is "the ability of individuals, families, and communities to promote and maintain health, prevent disease, and cope with their illness with or without the support of a health care provider".[11] Since the start of the COVID-19 pandemic and limitation of access to in-person care, the concept of self-care has received another level of attention from the HIV community. The AIDS 2020 virtual conference on "HIV, self-care and COVID-19: lesson for future of the HIV response" emphasized on publicizing HIV-related self-care.[12]

Studies in HIV have reported poor self-management among this population.[13-15] All three studies used the HIV self-management scale,[16] covering three domains of daily health practice (e.g., physical activity, diet, symptom management), social support (e.g., help from families, healthcare providers, and social network), and living with chronic HIV (i.e., accepting HIV, dealing with stigma). Webel et al. surveyed 260 HIV positive women in the United States and reported overall mean score of 2.28 ± 0.61 out of maximum score of 3. Mean self-management score for daily health practice was 2.19 ± 0.53, social support 2.0 ± 0.61, and living with chronic HIV 2.64 ± 0.43.[13] Similar studies with HIV positive individuals in China[15] and Korea[14] reported lower total and domain mean score.

The individual's behaviour is a central part of chronic disease self-management.[17,18] People with chronic conditions are "active agents in their own environments"[19] to enact and execute health-enhancing behaviours that could help with their HRQoL. Many factors could derail a person's effort to engage in healthy behaviours. Evidence-based approaches offer a solution to understand what works for or against a targeted behaviour. One such behavioural model is the COM-B model of behaviour. The COM-B model stands for "**C**apability", "**O**pportunity", and "**M**otivation" as three fundamental components interacting together to form a "**B**ehaviour". The model helps with understanding the potential influences of a certain behaviour. Each component of the COM-B model is subdivided to include all sources of behaviour.[20] For example, capability includes physical (skills) or psychological (knowledge) factors. Opportunity can be due to social or physical (environment) influences; motivation can be automatic (emotions) or reflective (beliefs). Each component of the COM-B model is further linked into the 14 domains of the Theoretical Domain Framework (TDF) providing a detailed and coherent framework for understanding a behaviour (Figure 1).[21]

Given that self-management remains as one of the challenges facing people living with the chronic nature of HIV, it is important to understand what influences self-management behaviours. . In this study we use the term goal instead of the behaviour. This is because self-management entails various behaviours and choices of those behaviours are very individualized. This study was not exclusive to a particular health-related behaviour; rather it probed health-related goals that mattered most to people living with HIV. Thus, the purpose of this study was to identify perceived barriers and enablers to acting on self-management goals among people living with HIV in Canada.

1. METHODS

1.1. Design

This was a cross-sectional survey study with thematic analysis of responses.

1.2. Participants and Recruitment

Data used for this study came from a randomized controlled trial on *goal setting in HIV* (Clinicaltirals.gov NCT04175795). The protocol for this trial has been published previously.[22] Briefly, the sample comprised of HIV positive adults, 35 years and above, living with HIV for at least one year who had access to the internet. People with dementia, co-morbidity affecting cognition, substance abuse, or life- threatening illnesses were excluded. Ethical approval was received from McGill University Health Centre Research Ethics Board (ABHN_goals 2020-5728).

Recruitment was from HIV sites in three provinces of Quebec, Toronto, and Vancouver. Participants were given a unique access code, and the link to access the goal setting survey platform either in French or English. For the main trial, the intervention group received a

personalized health outcome profile (as a feedback tool)[23] with instructions on goal setting and tips to improve brain health. The control group received only goal setting instructions and the tips. At the end of the trial participants in control group received their personalized health outcome profile as well.

1.3. Data collection

Data collection was through a survey platform (LimeSurvey hosted on a McGill server), accessible after electronically signing the consent form. Participants were asked to think of their goals as top 3 to 5 actions they would like to take to improve their health and write them in the format of free text in the assigned boxes. For each defined goal, participants were also asked about their self-regulatory plans i.e., barriers and potential solutions: "what are the things that make it difficult for you to meet your goal?" and "what is your plan for overcoming these difficulties". Participants had to provide their answers in free text form.

1.4.Data Analysis

For assessing goal areas, a thematic analysis followed by a deductive theory-based analysis using the International Classification of Function, Disability, and Health (ICF) Framework[24] was carried out. The ICF is a multipurpose classification system that provides a universal language across different disciplines describing health and health-related domains. The ICF provides a coding scheme across various health and functional states by across biopsychosocial and environmental domains.[25] The analysis was conducted in the following steps:

- Familiarization with the data by reading the goals and generation of initial themes. In this step either words from participants' quotes were borrowed or a general umbrella term was assigned.

- Emergent themes were then mapped to ICF domains. In this step the raw data was revisited in parallel to make sure the context had not been overlooked.

To identify barriers and enablers, a deductive theory-based analysis was done using two associated frameworks of COM-B and Theoretical Domains Framework (TDF).[20,21] For barriers and enablers, the analysis conducted in the following steps:

- Familiarization with the data by reading survey responses to questions related to barriers and plans.

- Mapping each defined barrier or plan first to the COM-B components.

- Further detailed diagnostic analysis of barriers and enablers by mapping the data within each COM-B component to the TDF domains.

Data analysis was reviewed by a co-investigator (NEM) upon which some necessary revisions were made.

2. RESULTS

Table 1 sumarizes characterisitcs of the cohort. A total of 110 participants completed the survey and defined 421 goals in free text format. Of these 421 goals, 26 did not have a defined barrier and 89 did not have a plan for overcoming the percieved barriers. Hence, a total of 395 responses for percieved barriers and 332 for percieved enablers remained for analysis.

Table 2 listes, in order of prevalence, the 10 most common goal areas. Mapping goal text threads to the ICF yeiled 47 ICF areas, including 28 level three and 19 level four codes. The most commonly nominated goal area was looking after one's self (108 goals) followed by managing diet and fittness (58 goals). Nonetheless, only 27.4% and 14.7% of the goals were focused on

these two areas. Supplementary Table 1 shows goal areas mapped to the ICF, frequency of the goals for those areas, as well as examples of the goals.

2.1. Barriers

Table 3 provides a detailed view of the perceived barriers defined by participants. Perceived barriers rooted almost equally in all three components of capability (35.7%), opportunity (34.4%), and motivation (30.8%).

2.1.1. Psychological Capability

Most common psychological barriers were those related to regulation of behaviour specifically difficulty breaking routines and habits such as dietary habits or dependency on coffee, alcohol, and cigarette:

> *"I crave towards eating sweet carbohydrates like cakes at expense of healthy food"* ID 50002-2

> *"Difficulty in switching TV off when had enough. Lots of TV is not good for back injury (too much time spent in sitting down position and static"* ID 10094-5

Other barriers within this domain were lack of knowledge (to be qualified for a job for example) and skills (such as social skills). Participants also mentioned lack of information on how to plan for their goals.

> *"gaining local education and experience – to make me qualify for employment that will boost my self-esteem"* ID 50002-4

> *"Socially awkward, shy not going out too much…"* ID 10227-3

2.1.2. Physical Capability

Fatigue, pain, and other health issues were described by participants as obstacles in achieving their goals:

"Douleurs encore présentes et problème du pancréas pas encore réglé" - *(pain still present and pancreas problem has not been fixed yet)* – ID 10102-4

"The pain is tough to battle and overcome, as by experience I know it will increase pain before it decreases it, and I have been less committed to the gym of late" ID 50054-1

2.1.3. Physical Opportunity

Lack of time was the most frequent barriers perceived by participants forming 55.3% of the barriers in this domain. Time constrain were mentioned due to job schedules, distance, taking care of others (partners or parents), or problem with time management.

"Working full time at a desk job that requires me to do work on a computer" ID 50154-2

"My work schedule can make this goal a little difficult since I work alternating dayshifts and nightshifts, so the consistency isn't there" ID 50121-3

"...je suis présentement [...ailleurs] en train de m'occuper de mon conjoint qui est paraplégique. Je m'occupe un peu de tout. Surtout le jardinage qui prend beaucoup de temps… je ne dispose pas de beaucoup de temps pour m'occuper de mes besoins" - (I am currently [away from home] taking care of my partner who is paraplegic. I do a bit of everything. Especially the gardening which takes a long time ... I don't have a lot of time to take care of my needs) – ID 20208-1

Second on this list was financial limitations due to unemployment, low income, or debt.

"I have been out of the workforce for several years now and away from my field. I may need recertification which will cost a few thousand dollars" ID 50092-2

Other perceived physical barriers to goal achievement were weather and COVID-19, as well as lack of or loss of resources. For example, not having a Partner, companion, or friend, loss of contacts, or closure of a training centre within the neighborhood.

"la fermeture de mon centre d'entraînement, la manque de routine le manque d'encadrement" – (the closure of my training center, lack of routine and supervision) – ID 20190-2

2.1.4. Social Opportunity

Reported barriers in this domain comprised only small portion of the barriers. Some participants mentioned work and eating habits of their partner or lack of support from their partner is what is prohibiting them from taking actions towards their goals:

> *"Conjoint qui est une personne solitaire et ne ressent pas le besoin de fréquenter beaucoup de personnes; il n'a pas d'intérêt à s'invertir dans plusieurs relations personnelles. Les connaissances en couple ont de la difficulté à accepter le fait que je sois seul lorsqu'ils nous invitent; ils n'acceptent pas que l'autre ne soit pas présent."* – (Spouse who is a solitary person and does not feel the need to hang out with a lot of people; he has no interest in getting involved in several personal relationships. The acquaintances couple have difficulty accepting the fact that I am alone when they invite us; they do not accept that the other person is not present) ID 10146-3

Other unmet social opportunities were problems with families, friends, or neighbours:

> *"Having friends visit from out of town. I tend to have people staying with my in the summer months. Going out for lunch or dinner too often"* ID 30076-4

2.1.5. Reflective Motivation

Most participants reported of their lack of motivation, procrastination, and laziness. Most text threats reflecting these themes were short. Some participants, however, added they do not see any obstacle expect "themselves" with no willingness and drive to plan and act on their goals:

> *"The motivation to get in the kitchen to cook for one person (me)"* ID 30071-2

> *"Motivation. Often I just want to keep my free time for myself"* ID 50039-3

2.1.6. Automated Motivation

Participants shared various emotions which they perceived as a barrier holding them back to move towards their goals with stress and anxiety being on top the list, among the others. Text

threats showed anxiety was mainly rooted in losing jobs, break ups at work or with the partner, and overthinking. Depression, loneliness, problem with self-acceptance, fear of others' judgement or the consequences, and insecurity were other states of emotions reported by participants:

> *"Like most people, I take what others say to heart and I am also very negative on my views on what people think and see of me"* ID 50066-4
>
> *"Overthinking & anxiety even when I'm actually well"* ID 10154-1

2.2. Enablers

Table 4 provides a detailed view of the perceived enablers defined by participants. Contrary to the barriers, perceived enablers were mainly defined to improve the capability domain (51.8%). Proportion of perceived enablers for the opportunity domain was 30.7%, and 17.5% for the motivation domain.

2.2.1. Psychological Capability

Wide range of psychological enablers were nominated by participants. Working on establishing a better habit in different aspects of health such as sleeping, eating, mental and physical exercise was the most common reported enabler. Enablers mentioned in this section were mostly potential solutions in response to the barrier "difficulty breaking habits" aimed at managing or changing the behaviour. For example, assigning a block of time for TV or internet and having a regular bedtime or setting rules such as no cellphone or tablet in bed or bedroom.

> *"Switching off TV same time as partner leaves TV for bed. Trying to consciously choose in advance the best programs to watch and how much per evening -- and not more than that"* ID 10094-5

"All my pills are now grouped in a canister on my side table and this is helping since I just removed the bottles from kitchen and bathroom to store in one location. I want to make my pill routine more scheduled just before bed" ID 50122-4

Other perceived enablers included seeking information (specific to the set goal such as targeted physical activity, job, or food), learning self-management, social, and organizational skills, and self-monitoring strategies:

"I will learn strategies and gain tools through the course that will help me to focus my hearing on things other than the ringing" ID 50045-2 who was dealing with tinnitus

"To set my watch to remind me to get up and move each hour and to get away from the computer screen" ID 50154-2

2.2.2. Physical Capability

Increasing physical activity and knowing ones' capabilities and limits were the two themes raised from participants' texts. Physical activity of different intensity was mentioned. Some participants were taking an exercise program and reported on continuation of that and others mentioned examples such as walking and biking, or meditation and yoga:

"Well, I started meditating again the other day at the park and I plan to meditate when I finish this survey!" ID 30108-3

"Walk at least 2 km a day or ride my bike 5 km a day" ID 50143-1

Although physical activity in any form of activity and body movement formed the majority of the perceived enablers in this section, some participants mentioned paying attention to their limits and knowing their capabilities might be what they need. For example, decreasing work hours and stopping physical activity before getting tired:

"Plus, d'organisation dans mes activités, savoir m'arrêter quand il est temps, prendre le temps de faire une auto-évaluation le soir avant de dormir." – (more organization in my

activities, knowing when to stop when it is time, taking the time to do a self-assessment at night before going to sleep) ID 10163-3

The interesting point noted among the text threats in this domain was examples of activities that could be done or added as part of work. For instance, some mentioned commuting by foot or bike, gardening, or even household chores could be a plan to overcome their perceived barrier:

> *"Ne pas attendre le transport en commun immobile mais plutôt marcher vers ma direction finale"* – (do not wait for the public transport but rather walk towards my final destination) ID 10064-5

2.2.3. *Physical Opportunity*

The top three emergent themes as perceived enablers were time management, financial plans, and seeking treatment. As for time management, some participants mentioned marking their activities on their calendar or assigning a day per week to their goal:

> *"Me donner 1 journée par semaine pour moi"* – (give myself one day per week for me) – ID 10175-4

> *"Book the day and keep it consistent"* ID 50163-2

Strategies for having a financial plan included increasing work hours, negotiating salary, taking a loan, and checking out the available employees' health benefits. Changing jobs or applying for a job were also mentioned by a few of participants:

> *"I'm going to push my work to provide as much funding as possible"* ID 50045-3

> *"I plan on taking a lower position where I can at least have a job. An entry level position in a Home Depot or Hotel (where I have some experience as well) will assist with resume and confidence"* ID 50092-2

Seeking treatment entailed making medical appointments and talking to a professional:

"En parler avec un professionnel. Je veux m'informer des programmes sur la santé mentale" – (talk to a professional, I want to learn more about mental health programs) ID 10027-4

"Premièrement, voir un médecin pour passer des tests" – (first, see a doctor for tests) ID 20240-2

Other perceived physical opportunities were better use of some available resources such as gyms and workout spaces at work and finding a partner or a companion:

"Get up and go to the gym. Find a gym partner to help motivate me to go" ID 50164-1

"Utiliser le gymnase lorsque je suis sur le bateau au travail alors que j'ai du temps libre" – (use the gym when I am on the boat at work when I have free time) ID 10138-2

2.2.4. Social Opportunity

Three main themes raised in this section: socialization plans, registration for school, a course, workshop, etc., and involving family and friends in the plans. Many creative examples were mentioned as part of the socialization plan: making a list of contacts, reading in a library, trying a new recipe and inviting friends over, or considering a volunteer work:

"I plan on reading my books at home on days that I am working, and on days that I am off, I can spend time at the library. I can only go to book club if I happen to not be working the day that the club meets once a month." ID 50121-3

Other perceived enabler mentioned by a few number of participants was to inform their families and friends about their goals and make it as a challenge and asking a friend or partner's accompany:

"work with family members to ensure I stick to the plan , to stop purchases of the high carbohydrates" ID 50002-2

"Je discute avec mes amis de mon objectif de réduire l'alcool. Je fais en ce moment un défi sans alcool depuis une semaine pour une période de 40 jours. Objectif avant d'aller

en vacances" – (I talk to my friends about my goal to cut down on alcohol. It has been a week I am doing a non-alcoholic challenge for a period of 40 days. [my] goal before going on vacation) ID 10156-5

2.2.5. Reflective Motivation

Self-motivation was the most frequent common reported enabler. Most participants were not clear about the "how" or "what" of self-motivation. Some, however, provided examples such as putting a deadline or engaging their partner in their planned activity as ways of motivating themselves:

> *"Make my boyfriend taste my new recipes"* ID 30071-2

> *"Just do it. Include a "chore" in each walk"* ID 30063-2

Optimism in forms of pray or hope, intention to act on the goal, beliefs about the consequences by reminding themselves about the health benefits of performing their goals (i.e., outcome expectancy), and belief about the capabilities by working on self-acceptance were other perceived enablers that could potentially help participants to move towards their set goals:

> *"Me dire que c'est bon pour la santé autant physique que mentale"* – (tell myself it is good for both physical and mental health) ID 20130-1

> *"More discipline when it comes to mindless television. I currently do the New York Times mini crossword daily; but find the Globe crossword frustrating. As with much of the above, it really is a matter of self-motivation, and reminding myself that if I do in fact wish to remain healthy, there are things to do"* ID 50137-4

2.2.6. Automated Motivation

A very small proportion of perceived enablers were focused on automated motivation. Working on emotions or managing emotions was perceived as one enabler. Text threats of participants contained strategies such as practicing detachment, let go of the past, and coping:

"Laisser les autres et accepter que les autres puissent faire les choses à leurs façons et en venir à un résultat similaire... sans être à ma façon" – (leave others and accept that others can do things their way and come to a similar result… without doing it my way) ID 10116-4

"Ne plus reculer Oublier le passé sombre" – (do not go back, forget the dark past) ID 10060-5

3. DISCUSSION

This study described perceived barriers and enablers to self-management goals defined by people living with HIV. Participants' goals were mainly focused on self-care and managing diet and fitness and to a lesser extent covered cognition, sleep, mobility, emotions, and social life. Some goal areas defined in this study were common with areas of life impact defined in the complete HIV cohort as well as other populations such as Multiple Sclerosis, Stroke, and Cancer; particularly for goals related to work, social life, and emotions.[26] This commonality could be due to the chronic yet sometimes unpredictable nature of challenges shared in these chronic conditions.[27] Literature on episodic disabilities in the context of employment have highlighted the ongoing challenges of individuals concerned with finding and retaining jobs mainly due to their intermittent work capacity.[28] Unpublished data of a Canadian survey in 2012 on more that 600,000 people with episodic disability and work disability showed key disability areas were related to mental health, pain, mobility, and flexibility.[28]

Defined barriers in this study were both intrinsic and extrinsic and reflected gaps in participants' capability, opportunity, and motivation. The main barriers interfering with taking action on self-management goals concerned psychological capability (difficulty breaking routines and habits, not knowing how to plan, and lack of information/skills), physical opportunity (lack of time, financial limitations, and lack of resources), and lack of motivation. These findings are in line

with previous research on self-management behaviours in HIV. Synthesis of studies on physical activity in people living with HIV showed that lower motivation, depression, and individuals' physiological capability (e.g., age, cardiorespiratory fitness) were factors relevant to lower engagement in physical activity [29]. Lack of time, knowledge of benefits, and limited physical and financial accessibilities were of other barriers to physical activity identified in qualitative studies with HIV+ men and women.[30,31]

An important finding of this study was that nearly half of the perceived enablers related to improving psychological capability. Emergent themes answered the important questions about "what" participants thought they need as means to "act" on their defined goals (i.e., knowledge, skills) and "how" they could do it (i.e., self-monitoring, reminders). Participants also identified enablers that could facilitate the perceived time and financial constraints (physical opportunity). These opportunities were mostly the ones deemed available to participants (e.g., using gym at work, increase working hours, employees' benefit). Awareness of the available opportunities does not necessarily translate to use which could be affected by other overriding factors (e.g., stress, fear of disapproval). Enablers relevant to motivation domain formed less than 20% of the total perceived enablers. This finding is supported by research using the behaviour change model.[20] In our study, the majority of perceived enablers were framed towards improving capability and providing opportunity. Having the necessary capability to act on health behaviour goals and being frequently exposed to opportunities where the act could be performed and repeated would lead to habit-forming processes. When a behaviour change into a habit, its persistency over time as a healthy behaviour is more likely guaranteed.[32] Essentially, it is difficult to get "motivated" to do something beyond one's capabilities and with restricted opportunities.

In this study participants' perceived barriers and enablers were according to their own defined self-management goals. This gave participants full autonomy to set goals on their own terms considering their circumstances and acceptable trade-offs.[33] Previous studies identified conflicting priorities between patients and care providers as a common reason for patients' passivity in collaborative goal setting exercises.[34-36] Nomination of goal areas and identification of barriers and enablers by people who are living a health condition have clinical relevance as it could set the stage to re-evaluate how representative the current HIV care is for addressing these issues. Participants in this study did represent some understanding of self-management by setting goals and identifying strategies. Yet, lack of detail in articulated goals as well as plans underpins the importance of self-management education.

People living with HIV use various sources of information for self-management strategies. Healthcare professionals, social support and media\ are the three most widely used sources for self-management advice.[37-39] The question is what could be done to improve chances of living a healthy lifestyle for HIV+ population? The current recommended healthcare visit for people living with HIV is every 3 to 6 months.[40,41] The frequency of these visits provides an opportunity for healthcare providers to probe more about person's challenges, monitor their HRQoL, and provide brief opportunistic advice relevant to person-reported concern. This process does not need to be time-consuming. Individualized approaches such as use of Patient generated Index (PGI) has been shown as one efficient tool that can provide insight into patients' view of their health[26] and help to open an effective health dialogue.

This study is not exempt from limitations. Participants were HIV+ older adults in Canada and the goals and related barriers and enablers are exclusive to this context. Also, participants in this study were mainly men, living with HIV for more than 20 years, and in stable HIV status (CD4

196

>500 cells/µL). Further research would be useful to explore goals and behavioural influences of women, younger adults and those newly diagnosed with HIV.

4. CONCLUSION

Improving HRQoL of people living with HIV is now an ultimate goal of HIV care and has also been proposed as the "fourth 90" target.[3] The conundrum of HRQoL in HIV population does not have an easy answer. Self-management is an empowering process, but more importantly it is a practiced skill and does not happen in isolation. It needs a collaborative partnership with healthcare providers and community organizations.[42] The routine appraisal of HRQoL, whether using a single question such as self-rated health status or the PGI, during each encounter could be a starting point to tackle the roots of poor HRQoL.

References

1.   UNAIDS. Global HIV & AIDS statistics — 2020 fact sheet. https://www.unaids.org/en/resources/fact-sheet. Published 2020. Accessed March 03, 2021.

2.   Trickey A, May MT, Vehreschild J-J, et al. Survival of HIV-positive patients starting antiretroviral therapy between 1996 and 2013: a collaborative analysis of cohort studies. *Lancet HIV*. 2017;4(8):e349-e356.

3.   Safreed-Harmon K, Anderson J, Azzopardi-Muscat N, et al. Reorienting health systems to care for people with HIV beyond viral suppression. *Lancet HIV*. 2019;6(12):e869-e877.

4.   Degroote S, Vogelaers D, Vandijck DM. What determines health-related quality of life among people living with HIV: an updated review of the literature. *Arch Public Health*. 2014;72(1):40.

5.   Lazarus JV, Safreed-Harmon K, Barton SE, et al. Beyond viral suppression of HIV – the new quality of life frontier. *BMC Med*. 2016;14(1):94.

6.   Harris TG, Rabkin M, El-Sadr WM. Achieving the fourth 90: healthy aging for people living with HIV. *Aids*. 2018;32(12):1563-1569.

7.   Grady PA, Gough LL. Self-management: a comprehensive approach to management of chronic conditions. *Am J Public Health*. 2014;104(8):e25–e31.

8.   Hessler DM, Fisher L, Bowyer V, et al. Self-management support for chronic disease in primary care: frequency of patient self-management problems and patient reported

priorities, and alignment with ultimate behavior goal selection. *BMC Fam Pract.* 2019;20(1):120.

9.   Zwar N, Harris M, Griffiths R, et al. A systematic review of chronic disease management. 2006. https://openresearch-repository.anu.edu.au/bitstream/1885/119226/3/final_25_zwar_pdf_85791.pdf. Accessed March 4, 2019.

10.   Reynolds R, Dennis S, Hasan I, et al. A systematic review of chronic disease management interventions in primary care. *BMC Fam Pract.* 2018;19(1):11.

11.   World Health Organization. Regional Office for South-East A. *Self care for health.* New Delhi: WHO Regional Office for South-East Asia; 2014.

12.   AIDS 2020 virtual conference — International panel discussion. HIV, self-care and COVID-19: Lessons for the future of the HIV persponse. *Am J Manag Care*. https://www.ajmc.com/view/we-must-make-hivrelated-selfcare-famous-panel-agrees. Published July 2020. Accessed March 03, 2021.

13.   Webel AR, Cuca Y, Okonsky JG, Asher AK, Kaihura A, Salata RA. The impact of social context on self-management in women living with HIV. *Soc Sci Med.* 2013;87:147-154.

14.   Kim GS, Chu SH, Park Y, et al. Psychometric Properties of the Korean Version of the HIV Self-Management Scale in Patients with HIV. *J Korean Acad Nurs.* 2015;45(3):439-448.

15.   Wang H, Chen A, Wan S, Chen H. Status and associated factors of self-management in people living with HIV/AIDS in Liangshan area, China: a cross-sectional study. *Patient Prefer Adherence.* 2019;13:863-870.

16.   Wallston KA, Osborn CY, Wagner LJ, Hilker KA. The Perceived Medical Condition Self-Management Scale Applied to Persons with HIV/AIDS. *J Health Psychol.* 2011;16(1):109-115.

17.   White CA. Cognitive behavioral principles in managing chronic disease. *West J Med.* 2001;175(5):338–342.

18.   Lee M, Park S, Lee KS. Relationship between Morbidity and Health Behavior in Chronic Diseases. *Clin Med.* 2020;9(1):121.

19.   Viding E. Individuals are active agents in their own environments. In: Sutton J, ed: The Psychologist; 2018:54-57.

20.   Michie S, Atkins L, West R. *The behaviour change wheel: A guide to designing interventions.* Great Britain: Silverback Publishing; 2014.

21.   Atkins L, Francis J, Islam R, et al. A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems. *Implement Sci.* 2017;12(1):77.

22.   Mozafarinia M, Rajabiyazdi F, Brouillette M, Fellows L, Knäuper B, Mayo N. 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]. *MNI Open Res.* 2020;4(1).

23.   Mozafarinia M, Rajabiyazdi F, Brouillette M-J, Fellows LK, Mayo NE. Development and usability of a feedback tool, "My Personal Brain Health Dashboard", to improve setting of self-management goals among people living with HIV in Canada. *Qual Life Res.* 2020.

24. World Health Organization. International classification of functioning, disability and health: ICF. In: Geneva: World Health Organization; 2001: https://apps.who.int/iris/handle/10665/42407.

25. Centers for Disease Control and Prevention. The ICF: an overview. https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf. Accessed Feb 12, 2021.

26. Mayo NE, Aburub A, Brouillette MJ, et al. In support of an individualized approach to assessing quality of life: comparison between Patient Generated Index and standardized measures across four health conditions. *Qual Life Res.* 2017;26(3):601-609.

27. O'Brien KK, Bayoumi AM, Strike C, Young NL, Davis AM. Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework. *Health Qual Life Outcomes.* 2008;6(1):76.

28. Adele Furrie Consulting Inc. People with episodic disabilities: Who are they and what supports do they need to obtain and retain employment? 2016. https://www.adelefurrie.ca/PDF/episodic_disabilities_in_canada_-_october_4_-_final.pdf.

29. Vancampfort D, Mugisha J, Richards J, De Hert M, Probst M, Stubbs B. Physical activity correlates in people living with HIV/AIDS: a systematic review of 45 studies. *Disabil Rehabil.* 2018;40(14):1618-1629.

30. Gray L, Schuft L, Bergamaschi A, Filleul V, Colson SS, d'Arripe-Longueville F. Perceived barriers to and facilitators of physical activity in people living with HIV: A qualitative study in a French sample. *Chronic Illn.* 2019:1742395319826638.

31.   Quigley A, Baxter L, Keeler L, MacKay-Lyons M. Using the Theoretical Domains
        Framework to identify barriers and facilitators to exercise among older adults living with
        HIV. *AIDS Care.* 2019;31(2):163-168.

32.   Gardner B, Lally P, Wardle J. Making health habitual: the psychology of 'habit-
        formation' and general practice. *Br J Gen Pract.* 2012;62(605):664-666.

33.   Christensen C, Fogg R, Waldeck A. Health for hire: Unleashing patient potential to
        reduce chronic disease costs. 2017. https://www.christenseninstitute.org/wp-
        content/uploads/2017/10/Health-for-Hire.pdf. Accessed January 2019.

34.   Blakeman T, Macdonald W, Bower P, Gately C, Chew-Graham C. A qualitative study of
        GPs' attitudes to self-management of chronic disease. *Br J Gen Practs.*
        2006;56(527):407-414.

35.   Newbould J, Burt J, Bower P, et al. Experiences of care planning in England: Interviews
        with patients with long term conditions. *BMC Fam Pract.* 2012;13:71.

36.   Buls P. Non-adherence versus goal mismatch: Which one is it? *Home Healthc Nurse.*
        2009;27(10):630-634.

37.   Schnall R, Liu J, Iribarren S. Information sources of self-care strategies for persons living
        with HIV. *Int J Med Inf.* 2018;111:1-6.

38.   Chou FY, Holzemer WL, Portillo CJ, Slaughter R. Self-care strategies and sources of
        information for HIV/AIDS symptom management. *Nurs Res.* 2004;53(5):332-339.

39.   Eller LS, Corless I, Bunch EH, et al. Self-care strategies for depressive symptoms in
        people with HIV disease. *J Adv Nurs.* 2005;51(2):119-130.

40.   Aberg JA, Gallant JE, Ghanem KG, Emmanuel P, Zingman BS, Horberg MA. Primary

        care guidelines for the management of persons infected with HIV: 2013 update by the

        HIV medicine association of the Infectious Diseases Society of America. *Clin Infect Dis.*

        2014;58(1):e1-34.

41.   Austin T, Traversy G, Ha S, Timmerman K. Canadian and international

        recommendations on the frequency of HIV screening and testing: A systematic review.

        Canada Communicable Disease Report. 2016;42(8):161-168.

42.   Dwarswaard J, Bakker EJ, van Staa A, Boeije HR. Self-management support from the

        perspective of patients with a chronic condition: a thematic synthesis of qualitative

        studies. *Health Expect.* 2016;19(2):194-208.
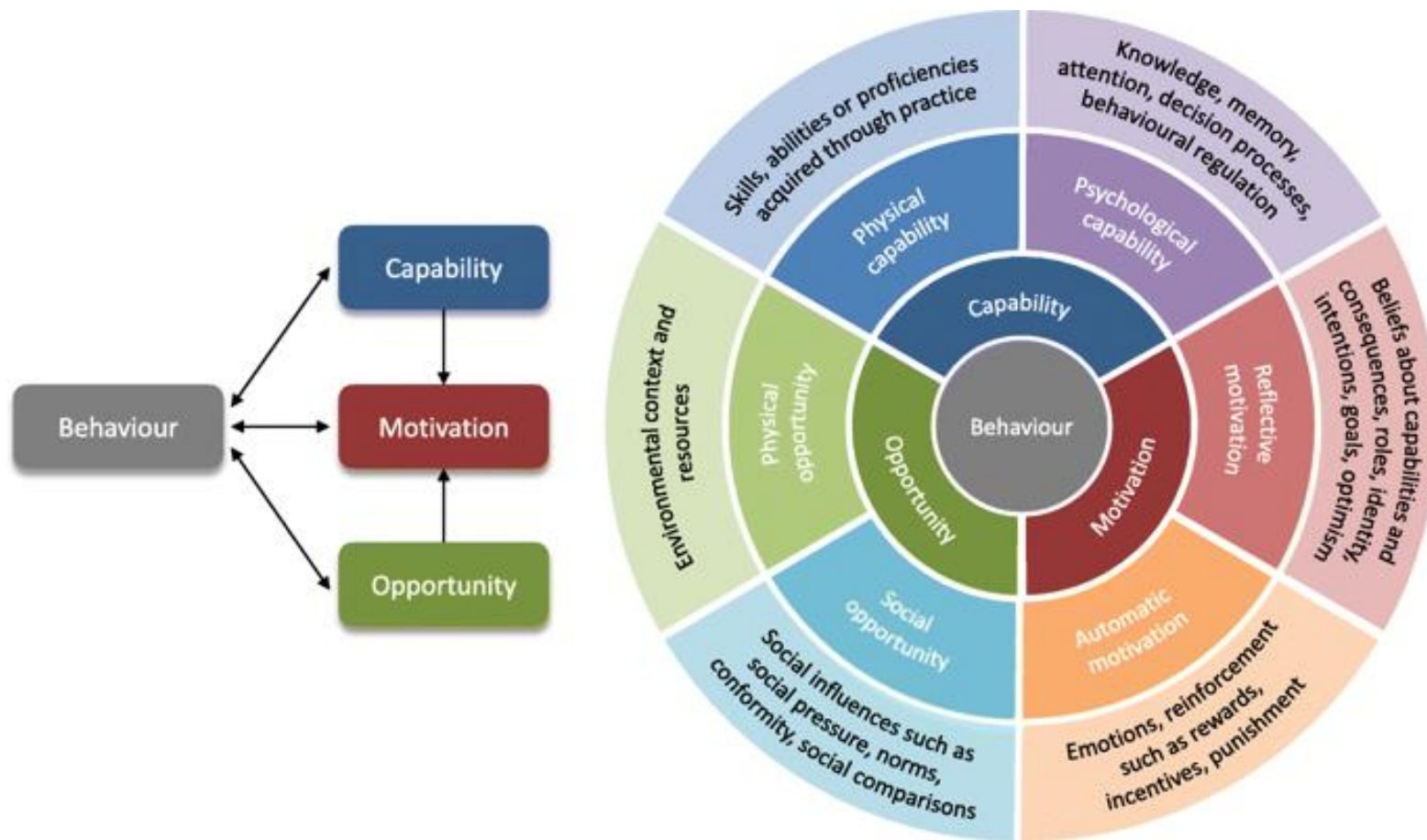
Figure 1 The COM-B model of behaviour. Michie S, Atkins L, West R. The behaviour change wheel: A guide to designing interventions. 2014. The third-tier links constructs of Theoretical Domain Framework to components of COM-B model.

Table 1 Characteristics of the cohort

	No. (%)
Number	110
Age (mean ± SD)	59.1 ± 7.7
Women	12 (10.9)
Men	50 (89.1)
Education	
< College	29 (26.4)
College	36 (32.7)
Undergraduate	23 (21.0)
Graduate	21 (10.1)
Years of living with HIV (mean ± SD)	22.1 ± 7.6
CD4 (mean ± SD)	613 ± 244
Nadir CD4 (mean ± SD)	200 ± 141.2
Comorbidity	
0	31 (28.2)
1	31 (28.2)
2	20 (18.2)
>2	28 (25.4)
Living status	
Alone	52 (47.3)
Working status	
Working > 15 h/w	45 (40.9)
Cognitive status	
Excellent	46 (41.8)
Good	30 (27.3)
Fair	34 (30.9)

SD: Standard Deviation

Table 2 Main goal areas mapped to the ICF

Rank	Goal area	Number of goals	%
1	Looking after one's health	108	28.0
2	Managing diet and fitness	58	15.0
3	Cognition (higher level of cognition, memory)	29	7.5
4	Sleep	24	6.2
5	Mobility (moving around, walking, climbing up the stairs)	23	5.9
6	Socializing	21	5.4
7	Handling stress	20	5.2
8	Regulation of emotions	13	3.4
9	Recreation and leisure	10	2.6
10	Family relationship	8	2.3
Total		314	81.5

Table 3 Self-reported barriers to goal achievement mapped to COM-B categories

Capability	%	Themes
Psychological	21.5	▪ Difficulty breaking routines and habits, for example: - Going to bed late or distraction mostly due to spending time on TV or social media - Craving sweets or junk foods, overeating - Dependency on coffee, alcohol, and cigarette ▪ Lack of information ▪ Don't know how to plan ▪ Being cognitively overload with work, Problem with concentration and lack of focus
Physical	13.3	▪ Fatigue ▪ Pain ▪ Other health issues (e.g., chronic insomnia, age and energy level, restricted mobility)
Opportunity		
Social	3.3	▪ Past traumatic experience at workplace (e.g., sexual harassment and bullying) ▪ Work and eating habit of the partner
Physical	31.1	▪ Time (due to job situation and being occupied at work, distance, taking care of others) ▪ Financial limitation ▪ Weather ▪ COVID-19 pandemic ▪ Lack of resources (e.g., not having a partner, companion, or friend)
Motivation		

Reflective	16.7	▪ Lack of motivation
		▪ Also mentioned as:
		  - Procrastination
		  - Laziness

Automatic	14.1	▪ Emotions such as: - Fear (of being judged or of the consequence) - Stress/anxiety (due to e.g., break-ups, or at work) - Depression ▪ Antisocial (misanthropy)

Table 4 Self-reported enablers to overcome goal difficulties mapped to COM-B categories

Capability	%	Themes
Psychological	41.0	▪ Work on establishing better habits, for example: - Set limited block of time for TV - Have a regular bedtime, enough hours of sleep, wake up earlier - Better eating and drinking habit (cook food at home, eat earlier, fresh ingredient, frozen bottles of water for summer walks, stop eating 3 hrs. befo[r]e bed, water rather than alcohol at supper, find alternative food choices, take fruits to work) - Mental health & cognitive exercise (e.g., read books, travel, learn a new language, relaxation techniques, breathing exercise) ▪ Seek information (related to activities, food, job, etc.) ▪ Learn skills (e.g., practice assertiveness, self-prioritization, perseverance) ▪ Developing social skills (e.g., one social activity/month, avoid overthinking[)] ▪ Organization (e.g., decluttering living space, keep pills near bed, clean the CPAP machine every morning, set 30 min on my days off work, save mone[y]) ▪ Self-monitoring strategies (e.g., set timer or alarms, make timetable of activities)
Physical	10.8	▪ Know my capabilities and limit ▪ Increase physical activity (e.g., continuation of an exercise program, gardening, walking, exercise at home, walk after supper, yoga)
Opportunity		
Social	10.5	▪ Socialization plans (cook new recipes and invite friends over, volunteer wor[k], join a club or community programs, visit family ▪ Register for a school, course, gym, etc. ▪ Avoid people or situations causing stress ▪ Ask a friend or partner for accompany
Physical	20.2	▪ Time management ▪ Financial plans (e.g., increase work hours, negotiate salary, employee's benefit for mental health, change job, apply for job ▪ Seek treatment (MD appointment, talk to a professional) ▪ Purchase necessary materials (e.g., shoes, books, bike, etc.) ▪ Retirement plan, leave of absence ▪ Change place of living ▪ Use gym at work ▪ Find a partner, friend, company/ do without partner
Motivation		
Reflective	15.4	▪ self-motivation (e.g., engaging partner in cooking, put a deadline) ▪ Optimism (e.g., pray, hope) ▪ Intention ▪ Beliefs about the consequences (e.g., placing a nicotine patch) ▪ Belief about the capabilities (e.g., self-acceptance)
Automatic	2.1	▪ Reinforcement (e.g., feeling happiness by paying off the debt, fitting in old cloths) ▪ Work on emotions (e.g., practice detachment, let go of past)

Supplementary Table 1 Goal areas mapped to the ICF, frequencies, and illustrative quotes for each ICF code

Participants reported goal areas mapped to the ICF		No.	(%)	Example quote
Temperament and personality, Energy and drive	b1265 optimism	4	1.04	Widower for a bit more than 1 year & hard to move on sometimes but must. Be happy go lucky.
	b126 temperament and personality	3	0.78	I want to improve my overall mood. To be a calmer, friendlier and more engaging person
	b1266 confidence	7	1.81	Avoir plus confiance en moi.
	b1301 motivation	1	0.26	Turn errands/chores into pleasure
	b1303 craving substances (that can be abused)	1	0.26	I will conquer my substance use problem by this summer through continuing to get professional care and taking anti-craving mess and, most important, by ending friendships and sexual relationships with substance users.
	b134 sleep function	24	**6.22**	Sleep 7 hours a night on a regular basis.
	b140 attention functions	2	0.52	Me concentrer dans mes projets.
	b144 memory function	9	**2.33**	I will improve my mental health throughout this time of self-isolation. I have a habit of watching tv and movies when I am at home and I can feel my memory is not as sharp as it used to be. Alzheimer's and Dementia also run in my family, so I want to strengthen my brain health. I will read one book per week from now until July and if I find an online course, I will sign up for it.
	b1521 regulation of emotions	13	**3.37**	Faire la paix avec le décès de ma mère
	b164 higher-level cognitive function	20	**5.18**	I want to challenge my mind and keep it sharp. Although I do a lot of reading at home, my plan would be to join the local book club (once a month), do crossword puzzles (buy a book of

				crossword puzzles to complete one daily, and spend more time at the library.
	b1642 time management	1	0.26	Manage my time better.
Sensory function & pain	b2400 tinnitus	1	0.26	My tinnitus as result of a workplace injury is off the charts. I will enroll in the Tinnitus Retraining Therapy course offered by the past President of the Canadian Hearing Society within the next month (pending financial capabilities as it's not covered by OHIP), in an effort to reduce the level of tinnitus and learn how to focus on other things. I want to do this to reduce frustration, reduce my constant fatigue due to waking up several times each night as a result of the ringing, and to get back to work full-time at full capacity. I will do this by committing to the course therapies on a daily basis.
	b2800 generalized pain	8	**2.07**	I want to lose 20 lbs. in the next 20 weeks. I want to do this so the pain in my lower back become less severe and I can breathe and sleep better. I will do this by doing cardio at the gym 4 times a week for 30-40 minutes.
Respiration function	b440 respiration function	1	0.26	Mieux respirer.
	b455 Exercise tolerance function (climbing stairs)	1	0.26	I will be improving my endurance within 3 months from today. I want to do this so that I am able to climb the stairs in my home without being so winded. I will do this by doing moderate endurance training exercises at the gym 2 times per week.
Movement function	b770 gait pattern function	1	0.26	J'améliorerai ma mobilité d'ici 2 mois suite à une intervention chirurgicale - remplacement du genou droit.
Learning	d1551 acquiring complex skills	2	0.52	Learn to be proficient at a new skill like "Sketchup".
General tasks and demands	d2401 handling stress	20	**5.18**	Gérer le stress en faisant des respirations profondes 3 fois par jour.
Walking & moving	d450 walking	7	1.81	Santé physique. Toujours par le programme de cardiologie préventive (CHUM), on me propose de marcher de 20 à 30 minutes au moins cinq (5) fois

				par semaine. Objectif; au fois 5 fois, par semaine, je sors pour une marche de 30 minutes.
	d455 moving around	15	**3.89**	Faire du vélo 3 heures par semaine.
	d4554 swimming	1	0.26	Recommencer la natation.
Self-care	d520 caring of the body part	2	0.52	Deal with my problems with my skin in the next 3 months. As I have had cancer and my family is prone to skin cancer. I want to have this checked out by a dermatologist, so I know where I stand with this issue. Because of the Covid-19 pandemic I have had to cancel an appointment but hope to make new one in a couple of months.
	d540 dressing	1	0.26	Pouvoir porter mes vêtements
	d570 looking after one's health	108	**27.98**	I would like to work towards become as active as I was in the past years. With a new job and commitments that I have made to it, I often find it difficult to be active after a very long day. I would like to create a daily routine that works for my busy lifestyle.
	d5701 managing diet and fitness	58	**15.03**	I will lose 35lb by June of this year through increased exercise and better diet.
	d599 self-care unspecified	2	0.52	Good health
Domestic life	d610 acquiring a place to live	2	0.52	I presently reside in a government subsidized apartment in a building which is not very well maintained, and because of bad air quality, it is very harmful to my health, i would like to eventually move to a much to a building with a cleaner and healthier environment.
	d630 preparing meals	1	0.26	Cook more food myself, not just leave it to my partner to do.
	d6402 cleaning living area	3	0.78	Je veux faire du ménage de mes garde-robes afin de me défaire des choses qui encombrent ma demeure. Je vais me demander si c'est encore utile, pratique ou être donner à d'autres qui en auraient besoin ou

				utile à eux. Je vais faire cela un peu tous les jours afin que ce projet soit terminé pour la fin du mois avril 2020.
	d650 caring for household	2	0.52	I would like to do renovations in my apartment in the next 6 months.
	d660 assisting others	1	0.26	Caring for my children[i]
Interpersonal interactions and relationships	d7200 forming relationships	2	0.52	My goal is to make new friends.
	d7201 terminating relationship	1	0.26	I want to ensure I have a completed divorce from my past partner in the next two months, so I can then have more options about who & how I choose to share my life. I have already sourced that my ex has passed away so I will be following up with family for a certificate of death to ensure closure.
	d760 family relationship	9	**2.33**	To visit family and friends and family and friends who all live in Ontario more often. I'm not very close to a good number of family members, but I do miss the ones with whom I'm closer to and i am afraid of aging and being alone.
	d770 intimate relationships	3	0.78	Trouver éventuellement un partenaire sexuel compatible pour combler mes besoins dans ce sens.
	d820 school education	1	0.26	Retourner à des études
Major life areas	d840 work preparation	1	0.26	To improve myself and qualify for market employment so as to get out of the ODSP[ii] by the next 2 years
	d8450 seeking employment	2	0.52	I will find a job and make money, in the next 6 months so I can feel more productive and be able to pay off my debts and go on vacations.
	d8500 self-employment	1	0.26	Mettre en pratique l'ensemble de mes expériences acquises pour m'auto gérer sans pression.
	d859 work & employment	1	0.26	Organiser et terminer à temps toutes les tâches administratives concernant ma vie professionnelle et personnelle (impôts, comptes, appel téléphonique, administration du condo,

				véhicule...etc.…etc.…) avant un départ pour 6 mois.
	d860 basic economic transactions	2	0.52	Take better care of my financial affairs to get rid of a lot of stress to develop a budget which I have never done before, be more responsible in spending frivolously and to try and save more.
	d870 economic self-sufficiency	2	0.52	I would like to work on financial planning.
	d879 economic life	6	1.55	My goal would be to become completely independent with regards to my living situation. Have a good paying job where I can afford to live on my own and save money.
Community, social, & civic life	d910 community life	1	0.26	To expand my social welfare by at least engaging in a social group once a month for the next 12 months by attending biweekly meetings.
	d920 recreation and leisure	10	**2.59**	Devote more time to reading for pleasure.
	d9205 socializing	21	**5.44**	I want to entertain friends at home at least six times in the next year. I want to do this so that I can maintain friendships and offer something back for people who invite me over often. I will do this by setting up a calendar of likely dates, sending invitations out early, and maintaining a file of menu possibilities.
	d9301 spirituality	1	0.26	Spiritual connection with My God and savior Jesus His son
Total		386	100	

---

[i] This code was chosen as the enabler mentioned for this goal was to take a leave of absence to have more time to take care of the children.
[ii] ODSP: Ontario Disability Support Program

Chapter 12: Discussion

The overall purpose of this thesis was to contribute pragmatic evidence towards goal setting capability of people living with HIV. The steps taken towards this global objective were presented in five manuscripts. This thesis used the example of HIV as one complex chronic condition to shed light on the continuing cross-cutting needs of these populations. This chapter presents a global discussion by addressing challenges faced and lessons learned through the different steps of this work.

Umbrella Review

The first manuscript in this thesis presented an umbrella review of goal setting interventions in the context of chronic conditions. The umbrella review allowed for a structured synthesis of the evidence given the extant literature on goal setting. Seven systematic reviews contributed data: three of high quality, three of moderate quality, and one low quality based on AMSTAR2 quality appraisal tool. Effects were inconsistent across reviews but, when there were effects, they were all small (see Manuscript 1, p. 56).

The small effect of goal setting was viewed as an expected outcome given goal setting is almost never the only applied component of self-management interventions for chronic conditions.

The process of conducting the umbrella review and providing a meaningful interpretation of diverse findings in the well accepted context of goal setting was an excellent learning experience. The insight gained spotlighted the concept of 'clinical heterogeneity'.[98] While interventions targeted the same outcomes and were similar enough to be grouped in a review, they had some differences evident in diverse approaches to goal setting as well as active goal

setting components. Added to this, is the differences inherent in chronic conditions – also varies from one case to the other – which may further contribute to the clinical heterogeneity.

Umbrella reviews are to identify the outcome of practice in its broadest context and help with making implementation recommendations. The expected small effect of goal setting on outcomes critical to improvement of health and longevity suggests incorporation of goal setting is justified as an integral part of self-management interventions. The review also uncovered a lack of systematic reporting on the different stages of goal setting so that the extent of goal exchange and patients' involvement in the process remains unclear. This called into a question patients' capabilities to set their own self-management goals in real life – an important process needed for the work of managing health in every day.

Goals are known to drive the behaviour performance so long as the person has gone through the "pre-decision" stage where a balance has been achieved between goal desirability and feasibility.[97] As stated in the mindful theory of action phases, individuals' desires or needs stem from the discrepancies they find between their current state and their ideal state (i.e., health reference point) which in turn lead to a choice – prioritization of the needs and choosing amongst them (pre-decision phase). This choice then needs to be turned into a goal (pre-action phase).[97] People living with a chronic condition need to ponder on the many overlapping demands caused by their situations which often becomes overwhelming and might lead to loss of focus or overlooking of the health needs. Management of chronic conditions is not just about the adherence to the medication regimen (the case of HIV as an example), but it is also about the lifestyle choices that affect person's condition. Adoption of self-management practice in daily life needs an improved understanding of modifiable health indicators by people living with chronic conditions so that they would identify areas that they could improve or maintain.

215

Dashboard

The development of the "My Personal Brain Health Dashboard" presented in manuscript II was an effort to call attention to the modifiable indicators of health-related quality of life. The fifteen evidence-based items listed on the Dashboard were chosen for their relevance to the health consequences of HIV[99] but are all applicable across chronic conditions. The structure of the +BHN cohort (some 856 HIV+ individuals followed longitudinally over a 4-year period (with on-going follow-up) with information collected across domains of a biopsychosocial model of HRQL[100] posed an opportunity to i) communicate the results back to participants and ii) foster self-reflection in HIV individuals. Offering feedback to participants on their study results is receiving a great attention from research partners and participants, though still remains as a debatable area.[101] Research data, however, is a heavy lifting for lay people if not appropriately translated into meaningful information about them. The Dashboard was developed as a visualization in order to increase awareness and help people gain personal insight by comparing and contrasting their data from different time frames.

Pilot testing for assessing the usability of the Dashboard provided a context to observe participants while interacting with their own data, probe reactions. The aim was to identify features of interest and those that were disliked, willingness to share data, and other context information or changes they wanted to have on the layout. The important feature of the Dashboard was its fast readability due to color coding the results to reflect how far or close they are compared to the optimal level.

Text Mining

Through the goal setting exercise as part of the pilot study, the prerequisite steps for text mining procedure, explained in manuscript III and IV, were tested. As presented in manuscript I, data on

216

goal formulation is limited to goal setting approach – prescribed, self-driven, or collaborative – and goal documentation using the common SMART approach or goal setting tools such as GAS or COPM. Thereby, specificity of the goal has been always measured and corrected by the clinicians or researchers. At population level, where people need to set goals based on their own calculation and decision, a pragmatic approach suitable for an uncontrolled setting is required. Considering the nature of goal data (text data), text mining algorithms deemed as a suitable alternative replacing human resources. Through this process, meaningful information from unstructured goal data was extracted to be classified in different clusters. To train the program to look for the goal criteria, a goal setting lexicon was defined.

There were a few methodological challenges in this stage of the work. First, normal written communication contains words with multiple meanings and words that could function as more than one part of speech (i.e., noun and verb). For the purpose of goal specificity, a dictionary-based (lexicon) approach was considered to guide selection of the words. For words which held more than one function, it was decided to list them under one criterion. For example, 'book' can function both as a noun and a verb – '…book a study room' or '…read a book'. Given the more frequent function of the word was as a noun, it was classified under 'noun' representing *specific* criterion of the goal. Second challenge was concerning compound words – words that are made up of two or more words. For instance, the word 'sign up' is an actionable verb. Through tokenization the word would be split into 'sign' and 'up' and loss its meaning. For this purpose, n-gram models were used to pair the words. This was mainly an issue for the French language.

Data gathered through the goal setting exercise were considered as a training data to test the text mining algorithms through iteration (pre- and post-adding synonyms) and troubleshoot the errors.

Application of text mining in the main trial demonstrated the potency of text mining techniques for measuring goal specificity. Strength of the process was in defining a custom dictionary (lexicon) to identify words in their correct concept (i.e., rule-based concept identification) and integration of participants' vocabularies to capture commonly used words.

One limitation of text mining context here was the volume and length of the strings. Usually, bigger data with longer strings lead to a better accuracy and precision of algorithms.[102] Also, accuracy of spell-checking algorithms are not 100%. Another limitation concerned words that represented metrics and time. For example, in natural speaking, differentiation between functions of the words such as 'month' or 'week' as an 'evaluation point' or a 'deadline' versus a 'recollection of a period of time' depends on the context and the words coming before and after (e.g., last month). Text mining removes the context and only evaluates the 'token'. Therefore, there is a possibility that these words have been counted incorrectly. These limitations are due to the complexity of the natural language and does not imply that the text mining results were false, or algorithms were not precise. In addition, these limitations did not affect the outcome (goal specificity) as text data for both groups were mined in the same manner.

Goal Components and Contents

Text mining provided the quantitative data that could be used in statistical modeling, in this context negative binomial regression. Estimated rate ratio for goal specificity indicated equal performance of both groups implying that the Dashboard did not have a positive effect on the number or specificity of the goals. Cognition did not affect goal specificity in this sample. To the knowledge of the PhD candidate, statistical estimation of goal specificity in the context of chronic conditions and particularly on unsupervised self-defined goals has not previously been attempted and so this is an original contribution to the field. While around 56% of the goals for

the whole sample had a minimum of two (noun or verbs + metrics or time) goal criteria, only a small proportion were SMART goals (15%). This implied that the majority of the HIV+ individuals did not move beyond the pre-decision phase to define 'what', 'how', 'how much', and 'when' of their goal. A methodological consideration in this context was the low uptake of the intervention. Dashboard was opened and read, but perhaps not used for goal formulation. This could be due to a number of reasons. First, living with a chronic condition that places significant constraints on a person's daily life could be mentally devastating and make the person choose a passive coping approach, absolving oneself from self-management responsibilities. Second, as the information was generated from their first and last visits, it could be that Dashboard did not seem to have an immediate benefit for the participants, a phenomenon known as 'delay discounting' where perceived value of something losses its magnitude because of the delay.[103] Despite these limitation, defined goals of both groups overlapped in eight areas with little difference in rank and were globally aligned with items on the Dashboard. The most frequent goals related to taking care of oneself and diet and fitness. For the future trials using personal profiles, it would be beneficial to improve participants' engagement by scaling up the Dashboard by making it more interactive and more timely with respect to the data collection time points. Digital technology offers opportunities in this direction. The Dashboard has the potential to be integrated into technological platforms (e.g., apps, data sharing platforms between clinicians-patients) so that health indicators, such as items on the Dashboard, get measured more frequently. With visualization techniques these data could be explored by both patients and clinicians where they can perform a temporal comparison.[104]

Despite methodological challenges, collection of self-defined goals in an open ended and unstructured textual format, was an opportunity to learn about health-related goals of HIV+

individuals without any communication barriers (e.g., time constrains, clinicians filling patient's blank spaces). Previous studies on in-clinic communication challenges reported of differences between patients and clinicians in terms of details and thinking.[105] In the context of HIV, unstructured format of goal data also allowed participants to share their emotions and sensitive data without worry or concern.

Readiness for Self-Management

The qualitative thematic analysis of perceived barriers and enablers was an important part of this thesis as it provided a real-world insight on self-management needs of the HIV population at the micro-level. The COM-B model of behaviour of change and elements of the Theoretical Domain Framework (TDF) used in the analysis of barriers and enablers, served not only as an explanatory model (identifying self-management needs) but as a change model too (identifying where to focus). The COM-B model proposes that people must feel that they are both psychologically and physically capable of doing the behaviour (capability), have the social and physical (also known as environmental) opportunity, and want or need to perform the behaviour more than other competing behaviours (motivation).[106] The important observation of this piece was that most participants defined the barriers and enablers to acting on their self-management goals at the individual level rather than provider (e.g., clinician) or system level which reflects on their understanding of their own capacity in managing their condition. Challenges were reported in domains of psychological capabilities and physical opportunities. Perceived enablers were also largely aligned with areas of difficulties. Defined enablers contained many practical self-management strategies with some in favour of triggering a behaviour or maintaining it – 'habit formation' (e.g., setting a timer, keeping medication in a fixed location). The relevance of habit formation to promotion of long-term healthy behaviours has been suggested in several

studies.[107-109] Gardner[110] suggests that habit formation leads to activation of a behaviour through associative learning. The underlying mechanism for a behaviour to be transformed into a habit is 'repetition' which implies performance of a simple action over and over in a same context leads to associative learning where external cues initiate the action.[111] This is what Gardner calls "automaticity" of a behaviour which helps with persistency of a behaviour over time with less effort. About 20% of the barriers defined by HIV+ individuals were related to motivation. It has been argued that choosing salient contextual cues relevant to participant's daily life will increase the likelihood of behaviour performance regardless of motivation level.[112]

Detailed list of barriers and potential enablers presented in this work have a great potential to inform the design of future behaviour change interventions. Barriers and enablers not only flagged problem areas in behavioural terms but specified what needs to be targeted with a full range of options nominated by people living the condition. Perceived enablers were identified across all components of the COM-B model indicating that people with HIV have the potential capacity to engage in self-management activities. Focusing on common challenges people face in real life and integrating person-oriented strategies would be a way forward to help people to help themselves and translate self-management concepts into everyday life.

The goals and perceived barriers and enablers provided in this work are priorities and needs of people who on average have lived for over 20 years with their chronic medical condition (HIV). This work showed that people living with HIV are capable of identifying their goal priorities as well as areas of challenge and potential facilitators. But they do not seem to be in a self-management position. Self-management is an ongoing learned skill and requires active engagement with the healthcare team. To master the skills, patients need to learn to set their wellness goal according to their condition and have the ability to implement lifestyle changes.

This is not an easy process. Only a very small proportion of participants were capable of setting SMART goals. The following quote from Karen Rodham, who argues self-management is yet to translate into practice, highlights the importance of ongoing collaborative and supportive approach in helping people situate themselves in a position to self-manage:

"*When the [chronic] condition 'arrives', the life thread (our narrative about our life) is cut. Some threads stay connected, but most are severed and fraying. Some of the remaining threads will need cauterising, whilst it may be possible to tie others back together. It takes time to work out what is possible, what is necessary and what may never happen. It is hard to accept that life as you used to know it has changed, and probably changed for ever*."[113]

Concluding statement

Overall, this thesis contributed evidence towards goal setting capability and important self-management needs of people living with HIV, as an example of a complex chronic condition. To target engaging people in managing their condition, enhancing goal capability is important. Harnessing technology for data collection and interactive communication seems to be a promising approach. Text mining techniques appeared promising although more data are needed to inform what words are commonly being used and what goal criteria are missing. The strengths and weaknesses of text mining approach for both goal evaluation and goal setting warrants further research.

References

1.   Chronic. In. *Merriam-Webster*. https://www.merriam-webster.com/dictionary/chronic1982.

2.   World Health Organization. *Noncommunicable diseases [Internet]*. 2017.

3.   Public Health Agency of Canada. Improving health outcomes – A paradigm shift. Centre for chronic disease prevention: Strategic plan 2016-2019. http://www.phac-aspc.gc.ca/cd-mc/ccdp-strategic-plan-2016-2019-plan-strategique-cpmc-eng.php#factors. Published 2016. Accessed January 2021.

4.   Marengoni A, Angleman S, Melis R, et al. Aging with multimorbidity: A systematic review of the literature. *Ageing Res Rev*. 2011;10(4):430-439.

5.   Roberts KC, Rao DP, Bennett TL, Loukine L, Jayaraman GC. Prevalence and patterns of chronic disease multimorbidity and associated determinants in Canada. *Health promotion and chronic disease prevention in Canada : Research, policy and practice*. 2015;35(6):87-94.

6.   Public Health Agency of Canada. *How healthy Canadians are? A trend analysis of the health of Canadians from a healthy living and chronic disease perspective*. Public Health Agency of Canada; 2017-04-11 2017.

7.   OECD. *Health at a Glance 2019*. 2019.

8.   Salive ME. Multimorbidity in older adults. *Epidemiol Rev*. 2013;35:75-83.

9.   World Health Organization. Non-communicable disease: key facts. https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases. Published 2018. Accessed March 2021.

10. Bernell S, Howard SW. Use your words carefully: What is a chronic disease? *Front Public Health.* 2016;4.

11. Tinetti Md ME, McAvay PhD GJ, Chang Md SS, et al. Contribution of multiple chronic conditions to universal health Outcomes. *J Am Geriatr Soc.* 2011;59(9).

12. Raina P, Gilsing A, Mayhew AJ, Sohel N, van den Heuvel E, Griffith LE. Individual and population level impact of chronic conditions on functional disability in older adults. *PLoS ONE.* 2020;15(2):e0229160.

13. Global Burden of Disease Study 2013 Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute and chronic diseases and injuries in 188 countries, 1990-2013: A systematic analysis for the Global Burden of Disease Study 2013. *Lancet.* 2015;386(9995):743-800.

14. Québec Commissaire à la santé et au bien-être. Current status of chronic diseases in Québec and response of the health and social services system : Summary. In: [Québec]: Commissaire à la santé et au bien-être; 2012: http://books.scholarsportal.info/viewdoc.html?id=/ebooks/ebooks0/gibson_cppc-chrc/2012-05-31/1/10544845.

15. Deeks SG, Lewin SR, Havlir DV. The end of AIDS: HIV infection as a chronic disease. *Lancet.* 2013;382(9903):1525–1533.

16. Public Health Agency of Canada. *Population-specific HIV/AIDS status report: People living with HIV/AIDS.* 2013.

17. Australian Institute of Health and Welfare. Chronic Diseases. http://www.aihw.gov.au/chronic-diseases/. Accessed March 2020.

18.   Public Health Agency of Canada. HIV and AIDS: For health professionals.

        https://www.canada.ca/en/public-health/services/diseases/hiv-aids/health-

        professionals.html. Accessed March 2020.

19.   Cachay ER. Human Immunodeficiency Virus (HIV) Infection. In. *Merck manual*.

        Kenilworth, NJ, USA: Merck & Co., Inc. .

20.   Antiretroviral Therapy Cohort Collaboration. Life expectancy of individuals on

        combination antiretroviral therapy in high-income countries: A collaborative analysis of

        14 cohort studies. *Lancet.* 2008;372(9635):293-299.

21.   World Health Organization. HIV: From a devastating epidemic to a manageable chronic

        disease. In: *Ten years in public health, 2007–2017: Report by Dr Margaret Chan,*

        Director-General, World Health Organization. Geneva: World Health Organization,

        Licence: CC BY-NC-SA 3.0 IGO.; 2017.

22.   Public Health Agency of Canada. Estimates of HIV incidence, prevalence and Canada's

        progress on meeting the 90-90-90 HIV targets. Public Health Agency of Canada.

        https://www.canada.ca/en/public-health/services/publications/diseases-

        conditions/summary-estimates-hiv-incidence-prevalence-canadas-progress-90-90-

        90.html. Published 2020. Updated December 2020. Accessed Feb 05, 2021.

23.   Katz IT, Maughan-Brown B. Improved life expectancy of people living with HIV: Who

        is left behind? *Lancet HIV.* 2017;4(8):PE324-E326.

24.   Samji H, Cescon A, Hogg RS, et al. Closing the gap: Increases in life expectancy among

        treated HIV-positive Individuals in the United States and Canada. *PLoS ONE.*

        2013;8(12):e81355.

25.   Hawkins KL, Brown TT, Margolick JB, Erlandson KM. Geriatric syndromes: New frontiers in HIV and sarcopenia. *AIDS.* 2017;31(Suppl 2):S137-S146.

26.   Serrano-Villar S, Gutiérrez F, Miralles, et al. Human Immunodeficiency Virus as a chronic disease: Evaluation and management of non-Acquired Immune Deficiency Syndrome-defining conditions. *Open Forum Infect Dis.* 2016;3(2):ofw097.

27.   Fries JF, Nesse RM, Schneider EL, Brody JA. Aging, natural death, and the compression of morbidity. *N Engl J Med.* 1984;310(10):659-660.

28.   Kingston A, Robinson L, Booth H, Knapp M, Jagger C. Projections of multi- morbidity in the older population in England to 2035: Estimates from the population ageing and care simulation (PACSim) model. *Age and ageing.* 2018;47(3):374-380.

29.   Safreed-Harmon K, Anderson J, Azzopardi-Muscat N, et al. Reorienting health systems to care for people with HIV beyond viral suppression. *Lancet HIV.* 2019;6(12):e869-e877.

30.   Millard T, Elliott J, Girdler S. Self-management education programs for people living with HIV/AIDS: A systematic review. *AIDS patient care STDS.* 2013;27(2):103-113.

31.   Wehby GL, Domingue BW, Wolinsky FD. Genetic risks for chronic conditions: Implications for long-term wellbeing. *The Journals of Gerontology: Series A.* 2018;73(4):477-483.

32.   Swendeman D, Ingram BL, Rotheram-Borus MJ. Common elements in self-management of HIV and other chronic illnesses: An integrative framework. *AIDS Care.* 2009;21(10):1321-1334.

33. Collaborators. GRF. Global, regional, and national comparative risk assessment of 79 behavioural, environmental and occupational, and metabolic risks or clusters of risks, 1990–2015: A systematic analysis for the Global Burden of Disease Study 2015. *Lancet.* 2016;388(10053):1659-1724.

34. Krebs P, Prochaska JO, Rossi JS. A meta-analysis of computer-tailored interventions for health behavior change. *Prev Med.* 2010;51(3):214-221.

35. Public Health Agency of Canada. *At-a-glance – How healthy are Canadians? A brief update.* Ottawa, Ontario, Canada2018.

36. Joshi A, Bhagwat N. The relation of the non-modifiable (destiny) and modifiable (free will) factors in metabolic derangements. *Indian J Endocrinol Metab.* 2018;22(6):722-723.

37. Wannamethee SG, Shaper AG, Whincup PH. Modifiable lifestyle factors and the metabolic syndrome in older men: Effects of lifestyle changes. *J Am Geriatr Soc.* 2006;54(12):1909-1914.

38. Liu Y, Ozodiegwu ID, Nickel JC, Wang K, Iwasaki LR. Self-reported health and behavioral factors are associated with metabolic syndrome in Americans aged 40 and over. *Prev Med Rep.* 2017;7:193-197.

39. Lin CH, Chiang SL, Tzeng WC, Chiang LC. Systematic review of impact of lifestyle-modification programs on metabolic risks and patient-reported outcomes in adults with metabolic syndrome. *Worldviews Evid Based Nurs.* 2014;11(6):361-368.

40. Lebel S, Mutsaers B, Tomei C, et al. Health anxiety and illness-related fears across diverse chronic illnesses: A systematic review on conceptualization, measurement, prevalence, course, and correlates. *PLoS ONE.* 2020;15(7):e0234124.

41. Bailey JM, Bartlem KM, Wiggers JH, et al. Systematic review and meta-analysis of the provision of preventive care for modifiable chronic disease risk behaviours by mental health services. *Prev Med Rep.* 2019;16:100969.

42. Adams C, Zacharia S, Masters L, Coffey C, Catalan P. Mental health problems in people living with HIV: Changes in the last two decades: the London experience 1990–2014. *AIDS Care.* 2016;28(sup1):56-59.

43. Williams E, Catalan J. The changing profile of mental health problems in people with HIV. *Psychiatry (Edgmont).* 2009;8(6):216-222.

44. U.S. Food and Drug Administration's (FDA's) Patient-Focused Drug Development Initiative. *The Voice of the Patient.* 2014.

45. Sherr L, Clucas C, Harding R, Sibley E, Catalan J. HIV and depression – a systematic review of interventions. *Psychol Health Med.* 2011;16(5):493-527.

46. Harris M, Brouillette MJ, Mayo NE, et al. Associations of loneliness with cognitive function and quality of life (QoL) among older HIV+ adults. Paper presented at: 9th International Workshop on HIV & Aging2018; New York, USA.

47. Remien RH, Stirratt MJ, Nguyen N, Robbins RN, Pala AN, Mellins CA. Mental health and HIV/AIDS: The need for an integrated response. *AIDS.* 2019;33(9).

48. Harris TG, Rabkin M, El-Sadr WM. Achieving the fourth 90: Healthy aging for people living with HIV. *AIDS.* 2018;32(12):1563-1569.

49.   Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. *Milbank Q.* 1996;74(4):511-544.

50.   Population and Public Health Division. Chronic disease prevention guideline, 2018. In: Care MoHaL-T, ed. Ontario: Queens' Printer of Ontario; 2018.

51.   Pasricha A, Deinstadt RT, Moher D, Killoran A, Rourke SB, Kendall CE. Chronic care model decision support and clinical information systems interventions for people living with HIV: A systematic review. *J Gen Intern Med.* 2013;28(1):127-135.

52.   Kendall CE, Shoemaker ES, Boucher L, et al. The organizational attributes of HIV care delivery models in Canada: A cross-sectional study. *PLoS ONE.* 2018;13(6):e0199395.

53.   Glasgow RE, Orleans CT, Wagner EH. Does the chronic care model serve also as a template for improving prevention? *The Milbank Q.* 2001;79(4):579-612, iv-v.

54.   Reynolds R, Dennis S, Hasan I, et al. A systematic review of chronic disease management interventions in primary care. *BMC Fam Pract.* 2018;19(1):11.

55.   Zwar N, Harris M, Griffiths R, et al. A systematic review of chronic disease management. 2006. https://openresearch-repository.anu.edu.au/bitstream/1885/119226/3/final_25_zwar_pdf_85791.pdf. Accessed March, 2019.

56.   Boucher LM, Liddy C, Mihan A, Kendall C. Peer-led self-management interventions and adherence to antiretroviral therapy among people living with HIV: A systematic review. *AIDS Behav.* 2020;24(4):998-1022.

57.   Cooper V, Clatworthy J, Whetham J, Consortium E. mHealth interventions to support self-management in HIV: A systematic review. *Open AIDS J.* 2017;11:119-132.

58. Nkhoma K, Norton C, Sabin C, Winston A, Merlin J, Harding R. Self-management interventions for pain and physical symptoms among people living with HIV: A Systematic review of the evidence. *J Acquir Immune Defic Syndr.* 2018;79(2):206-225.

59. Lorig KR, Holman H. Self-management education: History, definition, outcomes, and mechanisms. *Ann Behav Med.* 2003;26(1):1-7.

60. Britannica The Editors of Encyclopaedia. "Ought implies can". In. *Encyclopedia Britannica*. https://www.britannica.com/topic/ought-implies-can.

61. Schmidt H. Chronic disease prevention and health promotion. In: Barrett DH, Ortmann LH, Dawson A, Saenz C, Reis A, Bolan G, eds. *Public health ethics: Cases spanning the globe [Internet]*. Cham (CH): Springer; 2016.

62. World Health Organization. *World helath statisitics 2020 visual summary.* World Health Organization;2020.

63. Anuruang S, Hickman LD, Jackson D, Dharmendra T, Van Balen J, Davidson PM. Community-based interventions to promote management for older people: An integrative review. *J Clin Nurs.* 2014;23(15-16):2110-2120.

64. Lopez-Vargas PA, Tong A, Howell M, Craig JC. Educational interventions for patients with CKD: A systematic review. *Am J Kidney Dis.* 2016;68(3):353-370.

65. Vermunt N, Harmsen M, Westert GP, Olde Rikkert MGM, Faber MJ. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: A systematic review. *BMC geriatr.* 2017;17(1):167.

66.   Kuo CC, Wang RH. Appraisal of the application of empowerment elements and strategies: The example of chronic metabolic diseases. *Chung-Hua Hu Li Tsa Chih (Chinese Journal of Nursing)*. 2013;60(1):78-86.

67.   Parke HL, Epiphaniou E, Pearce G, et al. Self-management support interventions for stroke survivors: A systematic meta-review. *PLoS ONE*. 2015;10 (7) (no pagination)(e0131448).

68.   Van Hecke A, Heinen M, Fernandez-Ortega P, et al. Systematic literature review on effectiveness of self-management support interventions in patients with chronic conditions and low socio-economic status. *J Adv Nurs*. 2017;73(4):775-793.

69.   Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *JAMA*. 2002;288(19):2469-2475.

70.   Lawless MT, Drioli-Phillips P, Archibald MM, Ambagtsheer RC, Kitson AL. Communicating with older adults with long-term conditions about self-management goals: A systematic review and thematic synthesis. *Patient Educ Couns*. 2021.

71.   Rosewilliam S, Roskell CA, Pandyan AD. A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation. *Clin Rehabil*. 2011;25(6):501-514.

72.   Newbould J, Burt J, Bower P, et al. Experiences of care planning in England: Interviews with patients with long term conditions. *BMC Fam Pract*. 2012;13:71.

73.   Blakeman T, Macdonald W, Bower P, Gately C, Chew-Graham C. A qualitative study of GPs' attitudes to self-management of chronic disease. *Br J Gen Pract*. 2006;56(527):407-414.

74.   Buls P. Non-adherence versus goal mismatch: Which one is it? *Home Healthc Nurse.* 2009;27(10):630-634.

75.   Lenzen SA, van Dongen JJ, Daniels R, van Bokhoven MA, van der Weijden T, Beurskens A. What does it take to set goals for self-management in primary care? A qualitative study. *Fam Pract.* 2016;33(6):698-703.

76.   Christensen C, Fogg R, Waldeck A. Health for hire: Unleashing patient potential to reduce chronic disease costs. 2017. https://www.christenseninstitute.org/wp-content/uploads/2017/10/Health-for-Hire.pdf. Accessed January 2019.

77.   Lenzen SA, Daniels R, van Bokhoven MA, van der Weijden T, Beurskens A. Disentangling self-management goal setting and action planning: A scoping review. *PLoS ONE* 2017;12(11):e0188822.

78.   Siegert RJ, Levack WMM. Challenges in theory, practice and evidence. In. *Rehabilitation goal setting : Theory, practice, and evidence*. Boca Raton: CRC Press, Taylor & Francis Group; 2015:3-19.

79.   Turner-Stokes L. Goal attainment scaling (GAS) in rehabilitation: A practical guide. *Clin Rehabil.* 2009;23(4):362-370.

80.   Bovend'Eerdt TJH, Botell RE, Wade DT. Writing SMART rehabilitation goals and achieving goal attainment scaling: A practical guide. *Clin Rehabil.* 2009;23(4):352-361.

81.   Law M, Baptiste S, Carswell A, McColl MA, Polatajko H, Pollock N. *Canadian occupational performance measure.* 4 ed. Ottawa, Ontario, Canada: CAOT Publications ACE; 2005.

82. Doran GT. There's a S.M.A.R.T. Way to write management's goals and objectives. *Manag Rev.* 1981;70:35-36.

83. Schut HA, Stam HJ. Goals in rehabilitation teamwork. *Disabil Rehabil.* 1994;16(4):223-226.

84. McLellan DL. Introduction to rehabilitation. In: Wilson BA, McLellan DL, eds. *Rehabilitation studies handbook.* Cambridge, U.K.: Cambridge University Press; 1997:1-20.

85. Marsland E, Bowman J. An interactive education session and follow-up support as a strategy to improve clinicians' goal-writing skills: A randomized controlled trial. *J Eval Clin Pract.* 2010;16(1):3-13.

86. Randall KE, McEwen IR. Writing patient-centered functional goals. *Phys Ther.* 2000;80(12):1197-1203.

87. Latham GP. Goal-setting theory: Causal relationships, mediators, and moderators. In: Oxford University Press; 2016.

88. Locke EA, Shaw KN, Snarl LM, Latham GP. Goal setting and task performance: 1969-1980. *Psychol Bull.* 1981;90:125-152.

89. *Dictionary of quality of life and health outcomes measurement.* First ed: International Society of Quality of Life Research (ISOQOL); 2015.

90. Carver CS, Scheier MF. *Attention and self-regulation: A control theory approach to human behavior.* New York: Springer-Verlag; 1981.

91.   Earley PC, Perry BC. Work plan availability and performance: An assessment of task strategy priming on subsequent task completion. *Organ Behav Hum Decis Processes.* 1987;39(3):279-302.

92.   Klein HJ, Whitener EM, Ilgen DR. The role of goal specificity in the goal setting process. *Motiv Emot.* 1990;14(3):179-193.

93.   Lee M, Park S, Lee KS. Relationship between Morbidity and Health Behavior in Chronic Diseases. *Clin Med.* 2020;9(1):121.

94.   Viding E. Individuals are active agents in their own environments. In: Sutton J, ed: The Psychologist; 2018:54-57.

95.   Wagner EH, Bennett SM, Austin BT, Greene SM, Schaefer JK, Vonkorff M. Finding common ground: Patient-centeredness and evidence-based chronic illness care. *J Altern Complement Med.* 2005;11 Suppl 1:S7-15.

96.   van Seben R, Smorenburg SM, Buurman BM. A qualitative study of patient-centered goal-setting in geriatric rehabilitation: Patient and professional perspectives. *Clin Rehabil.* 2019;33(1):128-140.

97.   Gollwitzer PM. Mindset theory of action phases. In: Van Lange PAM, Kruglanski AW, Higgins ET, eds. *Handbook of theories of social psychology*: Sage Publications Ltd; 2012:526-545.

98.   Fletcher S. Benefits and barriers to clinical engagement with cancer consumer representatives in New Zealand. *Cancer Research Conference: 102nd Annual Meeting of the American Association for Cancer Research, AACR.* 2011;71(8 SUPPL. 1).

99. Collins LF, Armstrong WS. What It Means to Age With HIV Infection: Years Gained Are Not Comorbidity Free. *JAMA Netw Open.* 2020;3(6):e208023-e208023.

100. Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA.* 1995;273(1):59-65.

101. Macneil SD, Fernandez CV. Informing research participants of research results: Analysis of Canadian university based research ethics board policies. *J Med Ethics.* 2006;32(1):49-54.

102. Kotu V, Deshpande B. Text mining. In. *Data science : Concepts and practice.* Second edition. ed. Cambridge, MA: Morgan Kaufmann Publishers, an imprint of Elsevier; 2019.

103. Kable JW, Glimcher PW. The neural correlates of subjective value during intertemporal choice. *Nat Neurosci.* 2007;10(12):1625-1633.

104. Choe EK, Lee B, Zhu H, Riche NH, Baur D. Understanding self-reflection: How people reflect on personal data through visual data exploration. Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare; 2017; Barcelona, Spain.

105. Rajabiyazdi F, Perin C, Vermeulen J, MacLeod H, Gromala D, Carpendale S. Differences that matter: in-clinic communication challenges. Proceedings of the 11th EAI International Conference on Pervasive Computing Technologies for Healthcare; 2017; Barcelona, Spain.

106. Michie S, Atkins L, West R. *The behaviour change wheel: A guide to designing interventions.* London: Silverback publishing. www.behaviourchangewheel.com; 2014.

107. Rothman AJ, Sheeran P, Wood W. Reflective and automatic processes in the initiation and maintenance of dietary change. *Ann Behav Med.* 2009;38 Suppl 1:S4-17.

108. Bayley PJ, Frascino JC, Squire LR. Robust habit learning in the absence of awareness and independent of the medial temporal lobe. *Nature.* 2005;436(7050):550-553.

109. Gardner B, de Bruijn GJ, Lally P. A systematic review and meta-analysis of applications of the Self-Report Habit Index to nutrition and physical activity behaviours. *Ann Behav Med.* 2011;42(2):174-187.

110. Gardner B, Lally P, Wardle J. Making health habitual: The psychology of 'habit-formation' and general practice. *Br J Gen Pract.* 2012;62(605):664-666.

111. Neal DT, Wood W, Labrecque JS, Lally P. How do habits guide behavior? Perceived and actual triggers of habits in daily life. *J Exp Soc Psychol.* 2012;48(2):492-498.

112. Lally P, van Jaarsveld CHM, Potts HWW, Wardle J. How are habits formed: Modelling habit formation in the real world. *Eur J Soc Psychol.* 2010;40(6):998-1009.

113. Rodham K. Overrated: self-management. *Psychologist.* 2018;31:34-37.

Appendices

Goal evaluation guideline for text mining			
Goal component	Definition	Should answer…	What do we look for?
Specific	Goal is well defined for a specific health concern or need of the person and is clearly focused on the desired outcome	what do I want/need?	Concrete, well-defined nouns
Measurable	It is addressed as how the progress towards goal achievement is going to be assessed	how will I know I have been successful?	Words (including units of measure) reflecting methods of measurement, frequency, distance, change, etc.
Action-oriented	A clear description of the steps or activities (including small and focused steps). It is clear that either the individual takes an active stance or that the goal depends on other people.	what will I do to achieve my goal?	Action verbs whether it be physical or mental (as oppose to neutral verbs which do not clearly convey any function)
Time-bound	A clear date (or time frame) for the outcome of the goal to be achieved.	what is my targeted date for completion of the goal and reassessment?	A date or words reflecting duration, time frame, or deadline

This guideline is based on *SMART* criteria for goal formulation. "Realistic" component of *SAMRT* criteria has not been considered in this guideline. This is because if all the other criteria are considered in goal formulation, the goal is expected to be realistic.

Appendix 2 Tips on how to set your health goals

KEEP IN MIND THAT

To adopt a healthier lifestyle, it is important to set effective goals.
People who set SMART goals, manage their health better.
Here are some tips that might help you set your own goals:

→ **Be clear on what you want to improve**:

- ~~Health~~ → My diet

(Don't write my health which is too broad, instead choose a specific aspect for example: My diet)

→ **How are you going to meet your goal?**

- Be specific! And then be more specific!
  - Less fast food
  - Fewer snacks
    - One small bag of potato chips only once a week
  - Less alcohol

→ **How will you know if you met your goal?**

- Keep a record

→ **What actions do you need to do to meet your goal?**

- Clean out your cupboards of processed foods
- Re-learn to cook
  - Plan meals
- Go grocery shopping
  - Read labels

→ **Be realistic**

- What can you achieve today?!
- What can you achieve in a week?!
- What can you achieve in a month?!

→ **Give yourself room to grow.**

- Start with your cupboards, **then** plan some meals, **then** learn to cook

→ **Set the date! (between now and …)**

- By _____ (date) I will be eating freshly prepared meals at least 5 times a week.

Your goal should reflect what you need and want to do! It should be to your benefit!

Conseils pour définir vos objectifs de santé

GARDEZ EN TÊTE QUE

Pour adopter un mode de vie plus sain, il est important de se fixer des objectifs efficaces. Les personnes qui se fixent des objectifs SMART gèrent mieux leur santé. Voici quelques conseils qui pourraient vous aider à définir vos propres objectifs:

→ **Soyez clair sur ce que vous voulez améliorer :**

- ○ ~~Santé~~ → Mon régime

(N'écrivez pas ma santé qui est trop large, mais choisissez plutôt un aspect; exemple : Mon régime)

→ **Comment allez-vous atteindre votre objectif ?**

- ○ Soyez précis! Et puis soyez plus précis!
    - ▪ Moins de restauration rapide (fast food)
    - ▪ Moins de collations
        - • Un petit sac de chips seulement une fois par semaine
    - ▪ Moins d'alcool

→ **Comment saurez-vous si vous avez atteint votre objectif ?**

- ○ Tenir un registre

→ **Quelles actions devez-vous faire pour atteindre votre objectif ?**

- ○ Nettoyez vos placards d'aliments transformés
- ○ Réapprendre à cuisiner
    - ▪ Planifier les repas
- ○ Faire les courses
    - ▪ Lire les étiquettes

→ **Soyez réaliste**

- ○ Que pouvez-vous réaliser aujourd'hui ?
- ○ Que pouvez-vous réaliser en une semaine ?
- ○ Que pouvez-vous réaliser en un mois ?

→ **Donnez-vous de la place pour grandir.**

- ○ Commencez avec vos armoires, **puis** planifiez des repas, **puis** apprenez à cuisinier plus sainement.

→ **Fixez la date!**

- ○ Au plus tard le _____ (date), je mangerai au moins des plats fraîchement préparés 5 fois par semaine

Votre objectif doit refléter ce dont vous avez besoin et que vous voulez faire!
Cela devrait être à votre avantage!
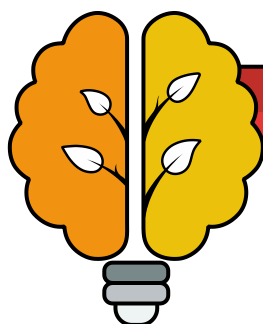
Action for Positive Brain Health Now

7 Simple Tips for Better Brain Health

Why is it important to focus on brain health?

Mild problems with thinking and memory are common in those living with HIV. The causes are not yet clear, but there are several steps you can take to protect and optimize your brain health.

What is good for the body is also good for the brain. A healthy lifestyle, engaging in interesting activities, exercising, managing stress and getting enough sleep all help to keep your brain healthy.

Take a look at the 7 tips in this document. These are tips that anyone can use, but only you know what is most important and relevant to your own life.

Begin by choosing one area where you think you could start making a difference today. Check out the recommended website or call the number provided for more information on what to do and how to get started. Set a realistic goal and give it a try for just a week or two. You may be surprised by how easy it is to build a healthier brain starting right now.

1. Stop Smoking

Nicotine is a powerful drug that changes the brain as well as the body. While smoking may briefly boost mood and energy, this effect fades quickly, leaving smokers feeling tired, "down", and craving another cigarette. Smoking reduces how much oxygen gets to the brain, and increases the risk of brain damage from stroke.

It's never too late to stop smoking and enjoy the health benefits that will follow. After just two days of not smoking, brain function begins to improve and risk of stroke is reduced.

For tools to help you quit, visit: The Canadian Cancer Society's website (www.smokershelpline.ca) or call their smokers' helpline toll free at 1-877 513-5333.

For more information on the effects of smoking, visit: http://www.hc-sc.gc.ca/hc-ps/tobac-tabac/quit-cesser/index-eng.php

If you only make one of the changes suggested here, this should be the one!

2. Challenge your Mind

Do mentally challenging activities each day. Play cards or board games with friends. Nurture creativity through hobbies or crafts. Learn a new language or take up line dancing!

For more ways to stimulate your mind, visit: http://alzheimer.ca/en/Home/About-dementia/Brain-health

3. Social Engagement

Keep in contact with your friends and relatives. Research shows that people who connect with friends or family in meaningful ways every day live longer and live better. Leave your computer and join a club, rally for a cause, volunteer, or take a walk with a friend.

Hi!

Hello

4. Move Your Body

Brain health is directly tied to physical health. Exercise can help you think more clearly and may protect against cognitive decline.

You can improve your health with as little as 2.5 hours of moderate to vigorous activity each week. Play a sport, walk briskly, jog, swim or bike – even sessions as short as 10 minutes repeated through the week can make a big difference to your brain and body. Get stronger by adding exercises such as push-ups, leg squats and crunches two or three times a week.

For ways to get active, visit:
http://www.catie.ca/en/practical-guides/managing-your-health/4#exercise

https://www.canada.ca/en/public-health/services/being-active/physical-activity-your-health.html

5. Manage Stress & Negative Moods

You can't eliminate stress, but you can learn to identify sources of stress and respond in healthier ways. Reduce your stress by setting realistic goals and managing your time effectively.

Deep breathing and other relaxation techniques, mindfulness meditation, and physical activity can help quiet the body and the mind. Yoga and other mind-body activities can promote mental and physical relaxation.
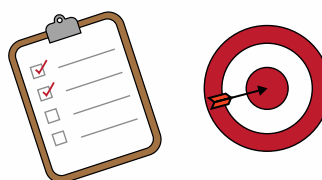
Anxiety and depression will affect your memory and your ability to think clearly. Speak with your healthcare provider if you feel anxious or sad most of the time for two or more weeks. Effective treatments include regular physical activity, short-term talk therapy or medication.

To learn more about managing stress and negative moods, visit:
http://www.catie.ca/en/practical-guides/emotional-wellness

6. Get A Good Night's Sleep

Your brain is very active during sleep. A good night's sleep helps improve memory and the ability to learn new information.

Develop a healthy sleep routine: Go to bed at the same time every night. Avoid naps during the day. Limit stimulants like coffee, cola and even chocolate, and avoid them entirely after 4 pm. Avoid large meals or strenuous exercise close to bedtime.

Talk with your doctor if you have trouble falling asleep, wake too early in the morning, sleep too much for two weeks or more or if your sleep is chronically poor. Loud snoring may also be a sign of a more serious sleep disorder that may need treatment.

To learn more about healthy sleep habits, visit:
http://www.catie.ca/en/positiveside/winter-2013/sleep-tight

7. Brain Detox

Many medications used to treat sleep problems, pain, or anxiety, including those available over-the-counter, can have negative effects on your memory and concentration. Review your medications with your physician. Limit your consumption of alcohol and recreational drugs.

(French)
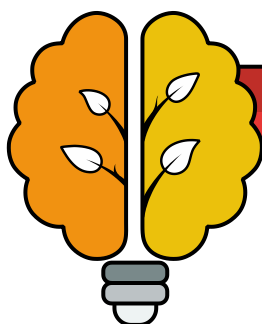
Action pour un cerveau en santé

7 Conseils simples pour améliorer la santé de votre cerveau

Pourquoi est-il important de se concentrer sur la santé de votre cerveau?

De légers problèmes de pensée et de mémoire sont fréquents chez les personnes vivant avec le VIH. Les causes ne sont pas encore claires, mais vous pouvez prendre plusieurs mesures pour protéger et optimiser la santé de votre cerveau.

Ce qui est bon pour le corps l'est également pour le cerveau. Un mode de vie sain, des activités intéressantes, de l'exercice, la gestion du stress et un sommeil suffisant contribuent à la santé de votre cerveau.

Jetez un coup d'œil aux 7 conseils de ce document. Ce sont des conseils que tout le monde peut utiliser, mais vous seul savez ce qui est le plus important et le plus pertinent pour votre vie.

Choisissez d'abord un domaine dans lequel vous pensez pouvoir commencer à faire la différence aujourd'hui. Consultez les sites web recommandés ou appelez le numéro fourni pour plus d'informations sur ce qu'il faut faire et comment commencer. Fixez-vous un objectif réaliste et essayez-le pendant seulement une semaine ou deux. Vous serez peut-être surpris de voir à quel point il est facile de développer un cerveau en meilleure santé dès maintenant.

1. Arrêtez de fumer

La nicotine est une drogue puissante qui change le cerveau ainsi que le corps. Bien que fumer puisse brièvement stimuler l'humeur et l'énergie, cet effet s'estompe rapidement, laissant les fumeurs fatigués, «down» et ayant envie d'une autre cigarette. Fumer réduit la quantité d'oxygène atteignant le cerveau et augmente le risque de lésions cérébrales dues à un accident vasculaire cérébral.

Il n'est jamais trop tard pour arrêter de fumer et profiter des bienfaits sur la santé qui suivront. Après seulement deux jours sans fumer, la fonction cérébrale commence à s'améliorer et le risque d'avoir un accident vasculaire cérébral diminue.

Pour des outils pour vous aider à cesser de fumer, visitez:
Le site web de la Société canadienne du cancer (www.smokershelpline.ca/fr-ca/home) ou appelez le service d'aide téléphonique de leurs fumeurs au numéro sans frais 1-877 513-5333.

Pour plus d'information sur les effets du tabagisme, visitez: http://www.canada.ca/fr/sante-canada/services/preoccupations-liees-sante/tabagisme/cesser-fumer.html

Si vous ne faites qu'un des changements suggérés ici, choisissez celui-ci!

2. Mettez votre cerveau au défi

Faites des activités mentalement stimulantes chaque jour. Jouez aux cartes ou à des jeux de société avec des amis. Encouragez la créativité par le biais de passe-temps ou d'artisanat. Apprenez une nouvelle langue ou faites de la danse en ligne!

Pour plus de façons de stimuler votre esprit, visitez: https://alzheimer.ca/fr/Home/About-dementia/Brain-health

3. Engagement social

Restez en contact avec vos amis et votre famille. Les recherches montrent que les personnes qui communiquent à chaque jour de manière significative avec leurs amis ou leur famille vivent plus longtemps et vivent mieux. Quittez votre ordinateur et allez prendre un café, joignez-vous à un club, faites du bénévolat ou aller prendre une marche avec un(e) ami(e).

Salut!

Bonjour

V1.0 _ 05Mar2019

244

4. Bougez votre corps

La santé du cerveau est directement liée à la santé physique. L'exercice peut vous aider à penser plus clairement et peut vous protéger contre le déclin cognitif.

Vous pouvez améliorer votre santé en faisant que 2.5 heures d'activité physique modérée à vigoureuse chaque semaine. Pratiquez un sport, marchez rapidement, faites du jogging, de la natation ou du vélo - même des séances d'une dizaine de minutes répétées au cours de la semaine peuvent faire une grande différence pour votre cerveau et corps. Devenez plus fort en ajoutant des exercices tels que des push-ups, des flexions sur jambes (squats) et des redressements assis deux ou trois fois par semaine.

Pour plus de façons d'être actif, visitez:
https://www.catie.ca/fr/guides-pratiques/vous-et-votre-sante/4

https://www.canada.ca/fr/sante-publique/services/etre-actif/votre-sante-activite-physique.html

5. Gérez le stress et les humeurs négatives

Vous ne pouvez pas éliminer le stress, mais vous pouvez apprendre à identifier les sources de stress et à réagir de manière plus saine. Réduisez votre stress en vous fixant des objectifs réalistes et en gérant votre temps efficacement.

La respiration profonde et d'autres techniques de relaxation, la méditation pleine conscience et l'activité physique peuvent aider à calmer le corps et l'esprit. Le yoga et d'autres activités corps-esprit peuvent favoriser la relaxation mentale et physique.

L'anxiété et la dépression affecteront votre mémoire et votre capacité à penser clairement. Parlez à votre professionnel de la santé si vous vous sentez anxieux ou triste la plupart du temps pendant deux semaines ou plus. Les traitements efficaces incluent une activité physique régulière, une psychothérapie à court terme ou des médicaments.

Pour en savoir plus sur la gestion du stress et des humeurs négatives, visitez:
https://www.catie.ca/fr/guides-pratiques/bien-etre-emotionnel

6. Passez une bonne nuit de sommeil

Votre cerveau est très actif pendant le sommeil. Une bonne nuit de sommeil contribue à améliorer la mémoire et la capacité d'apprendre de nouvelles informations.

Établissez une routine de sommeil saine: Couchez à la même heure chaque nuit. Évitez les siestes pendant la journée. Limitez les stimulants comme le café, le cola et même le chocolat et évitez-les complètement après 16 heures. Évitez les gros repas ou les exercices vigoureux près de l'heure du coucher.

Discutez avec votre médecin si vous avez du mal à vous endormir, si vous vous réveillez trop tôt le matin, si vous dormez trop pendant deux semaines ou plus ou si votre sommeil est chroniquement de mauvaise qualité. Un ronflement bruyant peut également être le signe d'un trouble du sommeil plus sérieux pouvant nécessiter un traitement.

Pour en savoir plus sur les habitudes de sommeil saines, visitez :
https://www.catie.ca/fr/visionpositive/hiver-2013/dormez-bien

7. Détoxifiez votre cerveau

De nombreux médicaments utilisés pour traiter les problèmes de sommeil, la douleur ou l'anxiété, y compris ceux en vente libre, peuvent avoir des effets néfastes sur votre mémoire et votre concentration. Vérifiez/Réexaminer vos médicaments avec votre médecin. Limitez votre consommation d'alcool et de drogues récréatives.

V1.0 _ 05Mar2019

```
The word is Avoid
<bound method Lemma.name of Lemma('avoid.v.01.avoid')>
<bound method Lemma.name of Lemma('debar.v.02.debar')>
<bound method Lemma.name of Lemma('debar.v.02.forefend')>
<bound method Lemma.name of Lemma('debar.v.02.forfend')>
<bound method Lemma.name of Lemma('debar.v.02.obviate')>
<bound method Lemma.name of Lemma('debar.v.02.deflect')>
<bound method Lemma.name of Lemma('debar.v.02.avert')>
<bound method Lemma.name of Lemma('debar.v.02.head_off')>
<bound method Lemma.name of Lemma('debar.v.02.stave_off')>
<bound method Lemma.name of Lemma('debar.v.02.fend_off')>
<bound method Lemma.name of Lemma('debar.v.02.avoid')>
<bound method Lemma.name of Lemma('debar.v.02.ward_off')>
<bound method Lemma.name of Lemma('avoid.v.03.avoid')>
<bound method Lemma.name of Lemma('keep_off.v.01.keep_off')>
<bound method Lemma.name of Lemma('keep_off.v.01.avoid')>
<bound method Lemma.name of Lemma('invalidate.v.01.invalidate')>
<bound method Lemma.name of Lemma('invalidate.v.01.annul')>
<bound method Lemma.name of Lemma('invalidate.v.01.quash')>
<bound method Lemma.name of Lemma('invalidate.v.01.void')>
<bound method Lemma.name of Lemma('invalidate.v.01.avoid')>
<bound method Lemma.name of Lemma('invalidate.v.01.nullify')>

The word is Biking
<bound method Lemma.name of Lemma('bicycle.v.01.bicycle')>
<bound method Lemma.name of Lemma('bicycle.v.01.cycle')>
<bound method Lemma.name of Lemma('bicycle.v.01.bike')>
<bound method Lemma.name of Lemma('bicycle.v.01.pedal')>
<bound method Lemma.name of Lemma('bicycle.v.01.wheel')>

The word is Breathing
<bound method Lemma.name of Lemma('breathing.n.01.breathing')>
<bound method Lemma.name of Lemma('breathing.n.
01.external_respiration')>
<bound method Lemma.name of Lemma('breathing.n.01.respiration')>
<bound method Lemma.name of Lemma('breathing.n.01.ventilation')>
<bound method Lemma.name of Lemma('breathe.v.01.breathe')>
<bound method Lemma.name of Lemma('breathe.v.01.take_a_breath')>
<bound method Lemma.name of Lemma('breathe.v.01.respire')>
<bound method Lemma.name of Lemma('breathe.v.01.suspire')>
<bound method Lemma.name of Lemma('breathe.v.02.breathe')>
<bound method Lemma.name of Lemma('breathe.v.03.breathe')>
<bound method Lemma.name of Lemma('breathe.v.04.breathe')>
<bound method Lemma.name of Lemma('breathe.v.05.breathe')>
<bound method Lemma.name of Lemma('breathe.v.06.breathe')>
<bound method Lemma.name of Lemma('rest.v.02.rest')>
<bound method Lemma.name of Lemma('rest.v.02.breathe')>
<bound method Lemma.name of Lemma('rest.v.02.catch_one's_breath')>
<bound method Lemma.name of Lemma('rest.v.02.take_a_breather')>
<bound method Lemma.name of Lemma('breathe.v.08.breathe')>
```

```
<bound method Lemma.name of Lemma('emit.v.01.emit')>
<bound method Lemma.name of Lemma('emit.v.01.breathe')>
<bound method Lemma.name of Lemma('emit.v.01.pass_off')>
<bound method Lemma.name of Lemma('breathing.a.01.breathing')>
<bound method Lemma.name of Lemma('breathing.a.01.eupneic')>
<bound method Lemma.name of Lemma('breathing.a.01.eupnoeic')>

The word is Bring
<bound method Lemma.name of Lemma('bring.v.01.bring')>
<bound method Lemma.name of Lemma('bring.v.01.convey')>
<bound method Lemma.name of Lemma('bring.v.01.take')>
<bound method Lemma.name of Lemma('bring.v.02.bring')>
<bound method Lemma.name of Lemma('bring.v.03.bring')>
<bound method Lemma.name of Lemma('bring.v.03.work')>
<bound method Lemma.name of Lemma('bring.v.03.play')>
<bound method Lemma.name of Lemma('bring.v.03.wreak')>
<bound method Lemma.name of Lemma('bring.v.03.make_for')>
<bound method Lemma.name of Lemma('bring.v.04.bring')>
<bound method Lemma.name of Lemma('bring.v.04.get')>
<bound method Lemma.name of Lemma('bring.v.04.convey')>
<bound method Lemma.name of Lemma('bring.v.04.fetch')>
<bound method Lemma.name of Lemma('bring.v.05.bring')>
<bound method Lemma.name of Lemma('bring.v.05.land')>
<bound method Lemma.name of Lemma('bring.v.06.bring')>
<bound method Lemma.name of Lemma('institute.v.02.institute')>
<bound method Lemma.name of Lemma('institute.v.02.bring')>
<bound method Lemma.name of Lemma('lend.v.01.lend')>
<bound method Lemma.name of Lemma('lend.v.01.impart')>
<bound method Lemma.name of Lemma('lend.v.01.bestow')>
<bound method Lemma.name of Lemma('lend.v.01.contribute')>
<bound method Lemma.name of Lemma('lend.v.01.add')>
<bound method Lemma.name of Lemma('lend.v.01.bring')>
<bound method Lemma.name of Lemma('fetch.v.02.fetch')>
<bound method Lemma.name of Lemma('fetch.v.02.bring_in')>
<bound method Lemma.name of Lemma('fetch.v.02.bring')>
<bound method Lemma.name of Lemma('bring.v.10.bring')>
<bound method Lemma.name of Lemma('bring.v.11.bring')>

The word is Bring down

The word is Bring in

The word is Build
<bound method Lemma.name of Lemma('physique.n.01.physique')>
<bound method Lemma.name of Lemma('physique.n.01.build')>
<bound method Lemma.name of Lemma('physique.n.01.body-build')>
<bound method Lemma.name of Lemma('physique.n.01.habitus')>
<bound method Lemma.name of Lemma('human_body.n.01.human_body')>
<bound method Lemma.name of Lemma('human_body.n.01.physical_body')>
<bound method Lemma.name of Lemma('human_body.n.01.material_body')>
```

Appendix 5

Goal setting lexicon – English – Version 3

Specific		Measurable		Action-oriented		Time-bound	
Specific	Ambiguous	Measurable	Unmeasurable	Optimal	Neutral	Yes	No
Ache	Accomplishment	Block	Adequate	Apply	Ascertain	April	Couple_of_months
Abs	Ability	By half	As best as	Arrive	Accept	August	
Acquaintance	Active	Flights	Better	Attend	Addressing	Autumn	
Alcohol	Active_lifestyle	Glass	Earlier	Bike	Adopt	Daily	
Alcoholic_beverage	Activity	Glasses	Earlier	Biking	allow	Day	
Aloneness	Adherent	heart points	Fewer	Breathe	Ask	Days	
Alzheimer	Alert	Hour	Gradually	Breathing	Assist	December	
Antiretroviral	Answers	hours	Less	Bring	Attempt	Evening	
Anxiety	Appearance	hr	Many	Bring down	Avoid	Every day	
Anxiousness	Appliance	hrs	More	Bring in	Be	Every evening	
Appointment	Attitude	Kg	More often	Build	Become	Every morning	
Asthma	Beverage	Kilogram	Much	Call	Care	Every night	
Asthma	Body	Kilometer	Regular	Choose	Cause	Every week	
Asthma_attack	Calm	Kilometer	Routine	Clear	Cease	February	
Anxiety	Community	kilos	Short distance	Climb	Challenge	January	
Beach	Diet	Km	Shorter	Consume	Change	July	
Bed	Eating habits	lbs	Some	Convey	Check	June	
Beverage	Effort	Lbs		Cook	Clean	March	
Bite	Encouragement	meal		Count	Conquer	May	
Blood pressure	Endeavour	Meter		Create	Consider	Month	
Book	Energy	Minutes		Cut back	Contact	Months	
Brain	Experience	move minutes		Cut down	Control	Morning	
Broccoli	Financial affairs	Once		Decrease	Cope	Next month	
Bus	Financial security	Ounce		Decrease	Deal	Next year	
Calorie	Fitness	pound		Deliver	Declutter	Night	
Carbohydrate	Food	pounds		Do	Delay	November	
Cardio	Goal	Servings		Draw	Demand	October	
Certificate	God	times		Drink	Determine	September	
Children	Health	Twice		Drive	Develop	Spring	
Cigaret	Health exercise			Eat	Devote	Summer	
Cigarette	Healthy_food			Enroll	Discontinue	Week	
Cinema	Investigation			Execute	Discover	Weekly	
Circuit	Life			Exercise	Discuss	Weeks	
Class	Lifestyle			Gain	Document	Winter	
Cognition	Mental health			Get	Drop off	Year	
Concentration	Mobile			Get together	Eliminate		
COPD	Pattern			Get up	End		
Counselling	People			Go	Engage		
Course	Physical health			Go away	Ensure		
Crossword	Physical strength			Increase	Entertain		
Date	Physical_fitness			Instruct	Establish		
Debt	Physical_score			Invite	Examine		
Dementia	Plan			Involve	Expand		
Depression	Problems			Learn	Expect		
Dermatologist	Procrastination			Lessening	Feel		

248

| Specific | | Measurable | | Action-oriented | | Time-bound | |
Specific	Ambiguous	Measurable	Unmeasurable	Optimal	Neutral	Yes	No
Desolation	Productive			Listen	Fight		
Diabetes	Productivity			Lose	Figure out		
Divorce	Project			Make	Find		
Doctor	Public			Make out	Find_out		
Drugs	Quality_of_life			Meditate	Finish		
Drugstore	Realistic			Meditate	Fix		
Elevator	Reasonable time			Meet	Follow-up		
Emphysema	Results			Memorise	Give		
Employment	Self			Memorize	Give up		
Endurance	Social			Move	Go_through		
Escalator	Social engagement			Obtain	Guide		
Exterior	Social interaction			Paint	Have		
Family	Social life			Participate	Help		
Fat	Social network			Pedalling	Hit		
Fatigue	Social_activity			Perform	Illustrate		
Film	Solutions			Pick	Improve		
Finance	Something			Practice	Inquire		
Focus	Vacation			Prepare	Introduce		
Food_for_thought	Visualization			Purchase	Journaling		
Food_intake	Well being			Read	Judge		
Food_market	Wellness			Redo	Keep		
Footstep	World			Reduce	Keep an eye		
Friend				Register	Leading		
Friends				Relax	Limit		
Friendship				Replace	List		
Fruits				Ride	Log		
Games				Run	Look_into		
Garden				Save	Love		
Grocery				See	Lower		
Grocery_store				Select	Maintain		
Group				Sign up	Manage		
Gym				Slow down	Move on		
Hearing				Stimulate	Notice		
Hearing aid				Store	Observe		
Herpes_zoster				Stretch	Pay off		
HIV				Study	Quit		
Home chores				Take	Re-establish		
Home renovation				Teach	Reach out		
Hospital				Tour	Realize		
House				Travel	Receive		
Intellectual_nourishment				Turn	Recognize		
Internet				Use	Recognize		
Isolation				Use_up	Reconnect		
Job				Visit	Record		
Jog				Volunteer	Recurrence		
Judgment				Wear	Reflect		
Language					Research		

Specific		Measurable		Action-oriented		Time-bound	
Specific	Ambiguous	Measurable	Unmeasurable	Optimal	Neutral	Yes	No
Laps					Review		
Library					Schedule		
License					See		
Lift					Set		
Locker					Socialize		
Loneliness					Spend		
Lonesomeness					Start		
Market					Stay		
Massage					Stay		
Mate					Stop		
McDonald					Strengthen		
Meals					Take care		
Meat					Take_on		
Medication					Talk about		
Medicine					Think		
Meditation					To have better understanding		
Meds					Track_record		
Meds					Trigger		
Memory					Trust		
Mind					Try		
Mobility					Try out		
Mom					Turn into		
Money					View		
Mood					Visualise		
Mother					Visualize		
Movie					Watch		
Mum					Watch over		
Muscle					Write		
Muscle strength							
Muscle waste							
Muscles							
Music							
Nap							
Netflix							
Nicotine							
Novel							
Nursing home							
Nutrient							
Online program							
Outdoor							
Outside							
Pace							
Pain							
Park							
Particular_date							
Partner							
Pharmacy							

Specific		Measurable		Action-oriented		Time-bound	
Specific	Ambiguous	Measurable	Unmeasurable	Optimal	Neutral	Yes	No
Pharmacy							
Phone							
Pic							
Pizza							
Pot							
Punctuate							
Puzzle							
Reading							
Relationship							
Relaxation							
Relaxation_method							
Repose							
Resistance							
Rest							
Salad							
School							
Sciatic							
Screen							
Shingle							
Shingles							
Shopping							
Shopping_centre							
Shopping_mall							
Sleep							
Smoking							
Snack							
Solitariness							
Spanish							
Spouse							
Stairs							
Steps							
Stomach							
Stress							
Sugar							
Substance use							
Suicide							
Supporter							
Swimming							
Tai-chi classes							
Television							
Temper							
Tennis							
Tenseness							
Tension							
Therapist							
Thinker							
Tinnitus							

Specific		Measurable		Action-oriented		Time-bound	
Specific	Ambiguous	Measurable	Unmeasurable	Optimal	Neutral	Yes	No
Tire_out							
Tiredness							
Tofu							
Tofu							
Tracker							
Treadmill							
TV							
Utilization							
Vaccine							
Vegan							
Vegetable							
Veggie							
Video conference							
Vitamins							
Walk							
Water							
Wear_down							
Wear_out							
Weed							
Weight							
Workout							
Yoga							
Zoster							

Goal Setting Lexicon – French – Version 3

Spécifique		Mesurable		Pragmatique		Temps	
Spécifique	**Ambigu**	**Mesurable**	**Incommensurable**	**Optimal**	**Neutre**	**Oui**	**Non**
Aide auditive	Activité	Bloc	Bon	Accomplir	Adresser	Année	Arriver un jour
Alcool	Activité sociale	De moitié	Longtemps	Aller	Affronter	Août	Jour_le_jour
Alimentation_rapide	Activités	Étage	Meilleur	Appeler	Aider	Automne	
Ami	Alimentation	Fois	Mieux	Appliquer	Aimer	Avril	
Amie	Aliments	Heure	Mieux	Apprendre	Améliorer	Décembre	
Amies	Apparence	Heures	Naturellement	Apprends	Arrêter	Du quotidien	
Amis	Bien-être	kg	Plus	Augmenter	Assurer	Été	
Anxiété	Chose	Kilogramme	Plusieurs	Boire	Avoir	Février	
Appareil GPS	Consacrer	Kilomètre	Raisonnable	Bouger	Cesser	Hebdomadaire	
Aqua	Corps	Kilos	Souvent	Choisir	Changer	Hiver	
Aqua	D'activité	km	Suffisamment	Consommer	Combattre	Janvier	
Argent	D'activités	lbs	Un peu	Contact	Combattre	Jour	
Ascenseur	Décès	Livres		Contracter	Commencer	jours	
Asthme	Défis	m		Coucher	Communiquer	Juillet	
Audition	Détresse	Mètre		Couper	Concentrer	Juin	
Audition	Économie	min		Cuir	Confier	Mai	
Ballad	Effort	minutes		Cuisiner	Conserver	Mars	
Bicyclette	Égard	par		Débuter	Continuer	Matin	
Boisson	Émission	Par nuit		Défaire	Control	Matinée	
Boisson gazeuses	Encouragement	Portions		Déménager	Créer	Mois	
Buddy	Engagement	Verre		Diminuer	Décider	Novembre	
Camarade	Enquête	Verres		Dormir	Découvrir	Octobre	
Cardio	Esprit			Économiser	Découvrir	Printemps	
Cardiologie préventive	Étude			Exercer	Découvrir	Semaine	
Cégep	Finance			Exercice	Développer	Semaines	
Centre commercial	Fitness			Faire	Développer	Septembre	
Centre_d'achats	Forme			Faire du vélo	Discuter	Soir	
Cerveau	Futur			Finir	Éliminer	Soirée	
Chant	Gerer			Inscrire	Entrelacer	Tous les jours	
Chips	Insécurité			Jouer	Espérer	Tous les soirs	
Chorale	La nourriture saine			Lire	Essai		
Chum	Mass musculaire			Manger	Essayer		
Cigare	Mode de vie actif			Marcher	Estimer		
Cigarette	Monde			Méditer	Être…		
Cinéma	Nourriture			Minimiser	Éviter		
Classe	Nutrition			Nettoyage	Fair confiance		
Cognition	Objectif			Obtenir	Fair une liste		
Collation	Personnes			Participation	Faire attention		
Compagnon	Physique			Perdre	Faire attention		
Comptabilité	Plan			Perte	Faire la paix		
Concentration	Postule			Porter	Faisant		
Conference	Problèmes			Pratiquer	Fixer		
Connaissance	Project			Prendre	Fréquenter des gens		
Consommation de boissons	Qualité			prends	Gérer		
Copains	Qualité de vie			Récupérer	Honorer		

Spécifique		Mesurable		Pragmatique		Temps	
Spécifique	Ambigu	Mesurable	Incommensurable	Optimal	Neutre	Oui	Non
Copines	Quelque chose			Réduire	Illustrer		
Cours	Réaliste			Regarder	Installer		
Date	Réponse			Registre	Maintenir		
Dépressif	Réponses			Rencontrer	Maintenir		
Dépression	Réseau social			Respirer	Mettre		
Dessert	Respect			S'engager comme volontaire	Modifier		
Douleur	Résultat			Se détendre	Obéir		
Eau	Rythme			Se faire des amis	Observer		
École	Santé			Se porter volontaire	Passer		
Écran	Santé			Se réveiller	Pensée		
Emploi	Science			Tendre	Planifier		
Épicerie	Score physique			Tricoter	Poser		
Escalator	Social			Utiliser	Recevoir		
Escaliers	Sociale			Visiter	Reconnecter		
Esprit	Solution				Régulariser		
Estime de soi	Solutions				Reprendre		
Étapes	Sport				Ressentir		
Étirement	Style				Rester		
Faillite	Travail				Retenir		
Famille	Vacances				Retourner		
Fast food	Vie social				S'adapter		
Fatigue					S'en sortir		
Film					Sélectionner		
Force musculaire					Socialiser		
Frites					Stimuler		
Fruit					Tenue d'un journal		
Fruits					Tisser		
Fumée					Trouver		
Fumer					Vivre		
Gardes-robes							
Glycémie							
Goûter							
Groupe							
Gym							
Haltére							
Humeur							
Intellect							
Isolement							
Jardin							
Jeux de memoire							
Kinésiologue							
L'alcool							
L'eau							
L'extérieur							
La prise de nourriture							
Langue							

Spécifique		Mesurable		Pragmatique		Temps	
Spécifique	Ambigu	Mesurable	Incommensurable	Optimal	Neutre	Oui	Non
Leçon							
Lecture							
Légume							
Légumes							
Livre							
Magasinage							
Maison							
Marche							
Marché							
Marches							
Mass musculaire							
Massage							
Matière							
Médicament							
Méditation							
Meds							
Mémoire							
Mémoire							
Mère							
Mobilité							
Mots croisés							
Muscles							
Musique							
Nager							
Natation							
Nourrir							
Ouïe							
Parc							
Partenaire							
Peinture							
Peinture							
pellicule							
Perte musculaire							
Pharmacie							
Plat congeals							
Plaza							
Poids							
Programmes en ligne							
Puzzle							
Régime							
Relâchement							
Relaxation							
Rendez-vous							
Rénovation							
Repas							
Repos							

Spécifique		Mesurable		Pragmatique		Temps	
Spécifique	Ambigu	**Mesurable**	Incommensurable	**Optimal**	Neutre	**Oui**	Non
Respirations							
Roman							
Seule							
Ski							
Solitude							
Sommeil							
Stress							
Sucre							
Sudoku							
Tai-Chi							
Téléphone							
Téléphone							
Thérapeute							
Tofu							
Vaccin							
Vélo							
Vêtement							
Viande							
Voyage							
Yoga							
Zona							

Self-reported barriers to goal achievement mapped to the COM-B categories.

Dashboard group (208 goals)	%		%	Control group (213 goals)
	30.2	**Capability**	36.6	

▪ Difficulty breaking routines and habits, for example:
  - Going to bed late or distraction mostly due to spending time on TV or social media (3)
  - Craving sweets or junk foods (9)
  - Dependency on coffee, alcohol, and cigarette (8)
▪ Lack of information (1)
▪ Don't know how to plan (9)
▪ Being cognitively overload with work, Problem with concentration and lack of focus (4)
	13.9	Psychological	26.3	▪ Difficulty breaking routines and habits, for example:
				  - Going to bed late or distraction mostly due to spending time on TV, internet, or social media (4)
				  - Craving sweets or junk foods, or overeating (23)
				  - Dependency on coffee or alcohol (especially for alcohol being considered as a fixed element of socializing) (8)
				  - Cigarette and substance abuse (7)
				  - Not something I usually do (e.g., taking stairs) (1)
				▪ Problem with memory and attention (4)
				▪ Lack of social skills (e.g., difficulty socializing, social anxiety, feeling socially awkward and shy) (3)
				▪ Lack of knowledge (to be qualified for the job) (1)
				▪ Don't know how to plan (1)
				▪ Being workaholic and not prioritizing health (no regular mealtime or bedtime) (4)

▪ Fatigue (13) ▪ Pain (12) ▪ Other health issues (e.g., chronic insomnia, age and energy level, restricted mobility) (4)	16.3	Physical	10.3	▪ Fatigue (9) ▪ Pain (7) ▪ Other health issues (e.g., chronic insomnia, sleep apnea, restricted mobility, ageing in general) (6)
	32.7	**Opportunity**	31.9	
▪ Past traumatic experience at workplace (e.g., sexual harassment and bullying) (1) ▪ Work and eating habit of the partner (4)	2.4	Social	3.7	▪ Work and eating habit of the partner and/or lack of support from the spouse (2) ▪ Problem with family and/or neighbours (3) ▪ Having friends around most of the time (3)

	30.3	Physical	28.2	
- Time (due to job situation and being occupied at work, distance, taking care of others) (34) - Financial limitation (16) - Weather (5) - COVID-19 pandemic (6) - Lack of resources (e.g., not having a partner, companion, or friend) (2)				- Time (due to job schedule and being occupied at work, distance, taking care of others, or just problem with time management) (34) - Financial limitation (unemployed, low income, debt) (17) - Weather (5) - Lost resources (e.g., closure of a training centre, not having a partner, companion, or friend, lost contacts) (4)
	28.4	**Motivation**	**27.6**	
- Lack of motivation (24) - Also mentioned as: - Procrastination (4) - Laziness (6)	16.4	Reflective	13.1	- Lack of motivation (11) - Also mentioned as: - Procrastination (5) - Laziness (12)
- Emotions such as: - Fear (of being judged or of the consequence) (5) - Stress/anxiety (due to e.g., break-ups, or at work) (17) - Depression (3) - Antisocial (misanthropy) (1)	12.0	Automatic	14.5	- Emotions such as: - Fear (of being judged, insecurity, fall and get injured) (5) - Stress/anxiety (due to e.g., losing jobs, overthinking) (7) - Depression (8) - Ego, self-acceptance (4) - Loneliness (3) - Social anxiety (e.g., not comfortable around people, being shy or introvert) (4)
	8.7	No barriers	3.8	

Self-reported enablers to overcome goal difficulties mapped to the COM-B categories.

Dashboard group (208 goals)	%		%	Control group (213 goals)
	40.4	Capability	41.3	
- Work on establishing better habits, for example: - Set limited block of time for TV, (4) - Have a regular bedtime, enough hours of sleep, wake up earlier, (4) - Better eating and drinking habit (cook food at home, eat earlier, fresh ingredient, frozen bottles of water for summer walks, stop eating 3 hrs. before bed, water rather than alcohol at supper, find alternative food choices, take fruits to work) (21) - Mental health & cognitive exercise (e.g., read books, travel, learn a new language, relaxation techniques, breathing exercise) (7) - Seek information (related to activities, food, job, etc.) (2) - Learn skills (e.g., practice assertiveness, self-prioritization, perseverance) (10) - Developing social skills (e.g., one social activity/month, avoid overthinking) (2) - Organization (e.g., decluttering living space, keep pills near bed, clean the CPAP machine every morning, set 30 min on my days off work, save money) (7) - Self-monitoring strategies (e.g., set timer or alarms, make timetable of activities) (7)	9.6	Psychological	7.5	- Work on establishing better habits, for example: - Have a regular bedtime, enough hours of sleep, wake up earlier, No tablet/cellphone in bed (5) - Better eating and drinking habit (regular mealtime, cook food at home, decrease junk foods and sweets, smaller portions, find alternative food choices, no wine during the week, modify grocery list) (20) - Mental health & cognitive exercise (e.g., read books, meditation, puzzles, breathing exercise, learn a new language) (10) - Seek information (related to activities, habits, etc.) (2) - Learn skills (e.g., practice assertiveness, self-prioritization, perseverance, tolerance, learn to cook, attend workshops for people with HIV) (13) - Organization (e.g., decluttering living space, save money) (7) - Self-monitoring strategies (e.g., daily track of activities, drinks, smoking, set reminders, journaling, use app, etc.) (15)
- Know my capabilities and limit (2) - Increase physical activity (e.g., continuation of an exercise program, gardening, walking, exercise at home, walk after supper, yoga) (18)	30.8	Physical	33.8	- Know my capabilities and limit (e.g., decrease work hrs.) (4) - Increase physical activity (e.g., continuation of an exercise program, running, biking, walking, exercise at home, alternate between mental and physical activity) (12)
	24	Opportunity	24.5	
Socialization plans (cook new recipes and invite friends over, volunteer work, join a club or community programs, visit family (9)	7.2	Social	9.5	Socialization plans (make a list of people who I can contact/talk, read in the library, volunteer work, invite small group of friends over, visit family/acquaintances) (8)

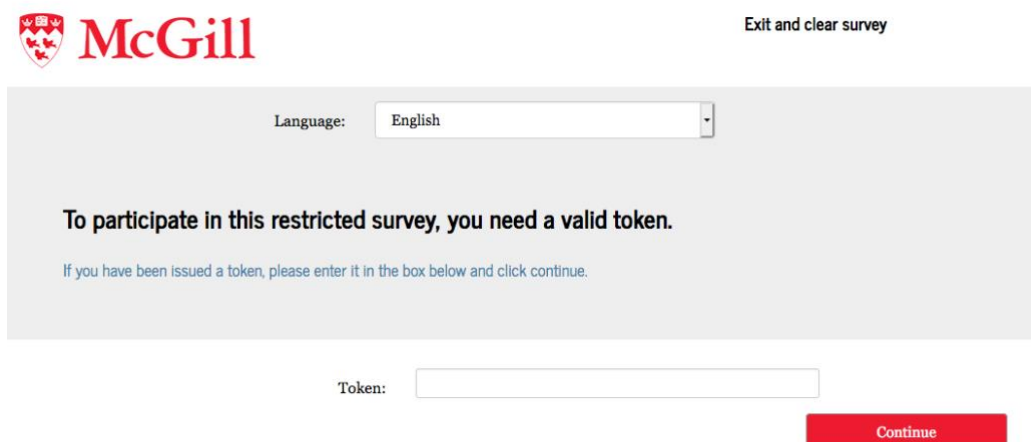|				
- Register for a school, course, gym, etc. (4) - Avoid people or situations causing stress (1) - Ask a friend or partner for accompany (1)				- Register for a school, course, workshop, etc. (5) - Involve friends/family, spouse in plans (e.g., inform friends about my goals and make it as a challenge (6) - Ask a friend or partner for accompany (1)
- Time management (4) - Financial plans (e.g., increase work hours, negotiate salary, employee's benefit for mental health, change job, apply for job (7) - Seek treatment (MD appointment, talk to a professional) (11) - Purchase necessary materials (e.g., shoes, books, bike, etc.) (6) - Retirement plan, leave of absence (3) - Change place of living (1) - Use gym at work (1) - Find a partner, friend, company/ do without partner (3)	16.8	Physical	15	- Time management (e.g., mark it in calendar, assign one day/week) (18) - Financial plans (e.g., increase work hours, take a loan) (2) - Communication to fix the environmental stress (1) - Change place of living (1) - Find a partner, friend, company (1) - Seek treatment (MD appointment, talk to a professional, braces) (8) - Take a sick leave (1)
	14	Motivation	13.6	
- self-motivation (e.g., engaging partner in cooking, put a deadline) (9) - Optimism (e.g., pray, hope) (5) - Intention (6) - Beliefs about the consequences (e.g., placing a nicotine patch) (3) - Belief about the capabilities (e.g., self-acceptance) (2)	12.1	Reflective	12.2	- self-motivation (no clear example) (9) - Optimism (e.g., pray) (1) - Intention (9) - Beliefs about the consequences (e.g., placing a nicotine patch, remind oneself of the health benefits) (7)
- Reinforcement (e.g., feeling happiness by paying off the debt, fitting in old cloths) (2) - Work on emotions (e.g., practice detachment, let go of past) (2)	1.9	Automatic	1.4	Work on emotions (e.g., coping (unrealistic optimism, ignorance), practice detachment, let go of past) (3)
	21.6	No plans	20.6	

Instructions on how to fill out the survey: "Goal-Setting in HIV"

1- Click on the survey link you have received in the email.
English: https://surveys.mcgill.ca/ls/856938?lang=en
French: https://surveys.mcgill.ca/ls/856938?lang=fr

2- You will see this page:

Type the token you received in the e-mail in
the box and click continue

3- You will see this page which has some information about the study. You have received most of it over the phone or may be through e-mail. You can scroll down the page and click "Next".

Here is a short summary of what this project and survey is about:

HIV is now known as a manageable chronic disease. As chronic illnesses persist throughout a person's life, a key strategy that can help individuals to improve health outcomes is self-management. Key activities in self-management are goal setting and the development of action plans to match people's needs, preferences, and health experiences. Some people are clear about their health priorities and can set their own health goals for areas they want to improve. For others, personal health information can help them make decisions about which goals are the most important and what actions they want to take. To this end, we have prepared a personalized health outcome profile for all participants who were either

• enrolled in the "Positive Brain Health Now" study

OR

- are participating in a new study, "Action for Brain Health Now".

Some have received the outcome profile and others will receive it after completion of the study.

All you have to do is write your health goals in the boxes assigned on this survey and answer a few short questions that follow each goal. If you can't finish the survey all at once, don't worry. You can click on **"Resume later"** button on the top left corner of the page that enables you to save your answers and continue finishing the survey at a later time.

We have also provided you with 1) *Tips to Improve Your Brain Health* to learn more about areas you can work on to improve your health and 2) *Tips on Goal-Setting* to familiarize yourself with how to write goals. You can print or download these documents if you wish.

Your participation will provide us with valuable information about health priorities of people living with HIV. Sharing your health goals with us will also help us understand what sort of information would be helpful for goal-setting.

By clicking on **"Next"** you will see the consent form of this study that contains all the detailed information you need to know about this study. After reading the information on the consent form you need to click on **"Yes, I agree"** to be directed to the survey page.

Next

Click on "Next" to go to the next page

4. On the next page, you will see the consent form. The information in the consent form may sound repetitive. But, according to the research regulation we had to put the consent form in the survey. When you are ready, you can scroll down and click on "I agree" and then "Next".

McGill

Resume later   Exit and clear survey   Question index ▾

Information and Consent Form

Please scroll down to read the information below which explains all the details about "Goal Setting in HIV" study. If you have any questions about this study you can either: E-mail the study coordinator at: amelie.duchesne-hamelin@muhc.mcgill.ca OR Call Centre for Outcome Research and Evaluation (CORE) at: (514) 934-1934, ext. 32188

After reading the information, please choose "Yes, I agree" at the end of the page and click next to start the survey.

*

Researcher responsible for the research study: Dr. Nancy Mayo, Ph.D., James McGill Professor, Department of Medicine School of Physical and Occupational Therapy, McGill University; Research Scientist, Center for Outcome Research and Evaluation, MUHC Research Institute; Phone: (514) 934-1934, ext. 32147

Co-Investigators: Maryam Mozafarinia, RN, Ph.D. student, Division of Experimental Medicine; Dr. Lesley Fellows, MD, Ph.D., Chronic Viral Illness service, Montreal Neurological Institute; & Dr. Marie-Josée Brouillette, MD, Associate Professor, Department of Psychiatry, Faculty of Medicine, McGill University, Research Scientist, Center for Outcome Research and Evaluation, MUHC Research Institute

Research Study Title: Effectiveness of a Personalized Health Profile on Specificity of Self-Management Goals Among People Living with HIV in Canada: A Blinded Pragmatic Randomized Controlled Trial

DECLARATION OF CONSENT

I have read the contents of this consent form and I am satisfied with the information I have received about the study. I understand that my participation is completely voluntary and that I can withdraw from the study at any time, without any penalty or consequences. I understand that by clicking on "Yes, I agree", I am electronically signing this consent form and declaring my consent to participate in this research study. Do you agree to partcipate in this study?

❶ Check all that apply

☐ **Yes, I agree**

Scroll down to get to the bottom of the page and click on "Yes, I agree" and then click on "Next" to start the survey

Previous

Next

5. Now, you will be on this page. You can read the information given on the page (and read the files you have received by e-mail) and start typing your goals in the box. The pictures below show where you need to write your goal.

McGill

Resume later   Exit and clear survey   Question index ▾

16%

Language: English ▾

Your Health Goals

We would like you to think of the top 3 to 5 actions you would like to take to improve your health condition and type them in the boxes below. For each goal you write, there are 3 very short questions you need to answer. You can familiarize yourself with how to write goals by reading the instructions given on *"Tips on Goal-Setting"*. You can also use the *"Tips to Improve Your Brain Health"* to learn more about areas you can work on to improve your health.

Remember the 7 simple tips for better brain health

Remember your goals should be SMART

S Specific
M Measurable
A Achievable
R Realistic
T Time-bound

Example: I will improve my mobility within 3 months from today. I want to do this so I can go on vacation without severe fatigue at the end of each day trip. I will do this by doing moderate exercises 3 times per week.

Type your goal in the box

Please type your goal in the box below

Read the questions and choose your answer by clicking on the circle below the number

* A: On the scale from 1 (least important) to 10 (most important), how important is this goal to you?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

* B: On the scale from 1 (great difficulty) to 10 (with no difficulty), how do you rate your current performance on this goal?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

• What are the things that make it difficult for you to reach your goal?

Read the question and type your answer in the box

• What is your plan for overcoming these difficulties?

Read the question and type your answer in the box

* C: On the scale from 1 (not confident) to 10 (completely confident), how confident are you that you can achieve your goal?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

Read the question and choose your answer by clicking on the circle below the number

Previous   Next

Click "Next" to go to the next page

264

6. you need to follow the same steps explained above and write 5 goals on areas of health that are important to you. When you are done writing your goals and answering questions related to each of your goals you can send us your answers by clicking on "Submit" as shown in the picture below.

C: On the scale from 1 (not confident) to 10 (completely confident), how confident are you that you can achieve your goal?

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○

Note: By clicking on "Submit", you can no longer go back and change your answers or resum later. If you have written all your goals and don't want to make any changes, click "Submit".

Previous

Submit

If you want to go back and check your answers or change your goals, you can do that by clicking on "Previous". You see this option at the end of each page on the left side.

When you are finished, click on "Submit" to send us your answers

7. That's all and now you are done with the survey!