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## Advantages of Wordless Instructions on how to Complete a Fecal Immunochemical Test: Lessons from Patient Advisory Council Members of a Federally Qualified Health Center

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### Abstract

Some patients face difficulty understanding Instructions for completing the fecal immunochemical test (FIT), a self-administered test to screen for colorectal cancer. We sought to develop and test low-literacy instructions for completing the FIT. Working in partnership with a Latino-serving Federally Qualified Health Center (FQHC) in the Portland Metro area, we developed and tested low literacy instructions for completing the FIT; the instructions contained 7 words [Mail within 3 days; *Devolver dentro de 3 dias*]. We conducted focus groups of Spanish-speaking patients on the advisory council of our partnering FQHC organization, and we gathered feedback from the project's advisory board members and clinic staff. We mailed a FIT kit to each patient, along with either (a) instructions written in English and Spanish, consisting of 415 words; or (b) low-literacy “wordless” instructions. We asked patients to complete the test before providing feedback. Our qualitative assessment showed that the wordless instructions were preferred over instructions consisting of words. Wordless instructions might aid efforts to raise the rates of colorectal cancer screening among low-literacy and non-English-speaking populations.

### Introduction

The fecal immunochemical test (FIT), a high-sensitivity test for detecting occult blood, is among the screening tests for colorectal cancer (CRC) recommended by the United States Preventive Services Task Force. The FIT is increasingly offered in primary care and is considered easier to complete than standard guaiac-based testing (gFOBT) because it relies on fewer stool samples and requires no dietary or medication restrictions.

Because fecal testing is generally performed at home, where patients do not have immediate access to the guidance of health care providers, it is critical that FIT instructions be easy to understand. While most FIT suppliers have developed instructions in multiple languages, communication challenges persist. For example, it can be difficult to ensure that instructions are delivered in the right language to the right patient. Moreover, worded instructions in any language often assume a level of health literacy that some patients may not possess.

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Previous research on the understandability of fecal test instructions is scarce. Limited available qualitative data from individuals at average risk for CRC showed that fecal occult blood test (FOBT) instructions were confusing and burdensome. Such instructions are thought to serve as a barrier to patient adherence to FOBT screening <sup>1</sup>.

As part of a larger pragmatic study that aims to raise the rates of colorectal cancer screening in Federally Qualified Health Centers (FQHCs), we report here on the design and testing of wordless instructions for using the FIT kit. While our instructions were specific to a single-sample FIT test that consists of a liquid-filled tube and collection brush, we hope that these instructions can be adapted and used for several types of fecal tests and for diverse populations and health care settings.

## Setting and Participants

The Screen to Prevent (STOP) program, a collaborative interaction between health research institutions and FQHCs, uses a pragmatic design to evaluate health system-based approaches to raising CRC screening rates among age-eligible patients who receive care at FQHCs. For the initial phase of STOP, our partnering organization is Virginia Garcia Memorial Health Center, and FQHC which serves more than 32,000 patients in four primary care clinics in the Portland, OR metro area. In 2012, the clinics served 4,902 unique patients aged 50–75, of whom 2,019 (41%) were Hispanic, 1,922 (39%) preferred to speak Spanish, and 2,152 (44%) were uninsured. Virginia Garcia organizes patient advisory councils that serve as a mechanism for involving patients and families in health care policy and program decisions.

## Program Description

We sought to develop FIT kit instructions that were understandable and easy to follow. Given this goal, our team worked with graphic artists at the Kaiser Permanente Center for Health Research to create two versions of FIT kit instructions: one having bilingual text (200 English words and 215 Spanish words) and photographs; and one having only 9 words (4 English and 5 Spanish) and pictographs. Because test accuracy relies on having samples processed within a limited number of days after collection (optimally within several days, but up to 2 weeks), we aimed to emphasize the consistent and accurate reporting of collection date. We were also aware of the multiple languages spoken by patients in our diverse study setting; accordingly, we sought to develop instructions using as few words as possible.

## Program Evaluation

We obtained feedback on the instructions from three groups: (1) Spanish-speaking patient advisory council members of Virginia Garcia Memorial Health Center; (2) clinic personnel at Virginia Garcia Memorial Health Center, and (3) members of the stakeholder advisory board for the STOP program (which included clinic representatives, policy-makers, and patient advocates, among others).

A project staff member attended a meeting of the patient advisory council (the council meets monthly), explained the project, and invited members to participate. All prospective participants provided their name and mailing address and were told that they would receive a series of mailings (a project introduction letter, FIT kit, and reminder postcard).

We asked patients to follow the instructions provided with the kit, with the exception of mailing the kit to the laboratory. Four weeks later, at a subsequent patient advisory council meeting, we conducted a focus group to assess patient reactions to the mailed materials and

identify areas for improving the materials. We asked patients for their overall reaction to the kit instructions, their specific reactions to the images and content, and whether they had any doubt that they had completed the test correctly. Additional questions addressed how likely the patients would be to recommend FIT testing to a friend, and what they perceived to be the barriers and facilitators to completing the kit.

We also presented the wordless instructions to 4 clinic personnel and 16 members of the STOP advisory board, who were asked to state their reactions to the look and feel of the instructions and to provide suggestions for how to improve them. We refined the FIT kit instructions based on the reactions and suggestions we documented during data collection. A revised version is provided in Figure 1.

### **Feedback from patient advisory council members**

All 10 patients were Hispanics, spoke Spanish, and were between the ages of 27 and 56 years. Nine were female. All patients, irrespective of whether they received the wordless or bilingual worded instructions, reported being able to understand the instructions and complete the test. However, all patients reported that they preferred the wordless instructions over the bilingual instructions. Patients did not have a disgust reaction to the graphic depiction of the fecal sample, and some noted the importance of that image in emphasizing the small amount of fecal matter needed for the test. Patients reported that the wordless instructions also appeared less intimidating than the worded instructions, which gave the patients ease in completing the test.

The patients offered some minor suggestions for improving the instructions, including using the format “MM/DD/13” rather than the open-ended “\_\_\_/\_\_\_/\_\_\_” to capture date, as the customary notation in most Latin American countries is for day to precede month. This modification could improve the systematic and accurate capture of date information. All participants noted that they would recommend CRC screening to their eligible friends because of the ease of the test.

### **Feedback from clinic staff and STOP CRC advisory board members**

Clinic staff and advisory board members also preferred the wordless instructions. Their perception of the date field, however, differed from that of patients. Clinic staff raised the concern that including the instruction “return immediately” might scare some patients. Advisory board members suggested “return within 3 days” as a less intimidating alternative.

## **Discussion**

Our wordless FIT kit instructions may be useful to a variety of health systems seeking to improve their CRC screening rates through the use of fecal testing. Our preliminary findings show high understandability and acceptance of the wordless instructions and a preference for wordless instructions over worded bilingual instructions.

A notable strength of our study was the innovative strategy of mailing two versions of the instructions and fecal test to patient advisory council members prior to soliciting feedback. This direct comparison allowed us to assess the true understandability of the instructions.

Previous research has shown that patients who are mailed a fecal test raise concerns about mailing biohazard material (i.e. fecal matter)<sup>2</sup>. This concern leads some patients to hand-deliver, rather than mail, their completed tests to the clinic. Our instructions did not directly address this concern; further refinements may be needed to reassure patients about the safety of mailing their samples.

This study has some important limitations. Members of our patient advisory councils may differ from general clinic patients in some important ways. It is possible that such members may have higher levels of health literacy, most were female, and some were younger than the recommended age for colorectal cancer screening. Thus, the generalizability of our findings may be limited. Further testing of the instructions may be needed. Nevertheless, we hope that our wordless FIT instructions can be used and further tested in diverse health systems.

Advisory council members preferred our wordless FIT instructions over instructions with words and considered them easy to understand. Patients favored the look of the wordless instructions, specifically noting the helpful illustration of the small amount of stool needed for the test. Providing understandable instructions on how to complete a FIT might aid efforts to raise CRC screening rates among low-literacy and non-English-speaking populations. Such instructions might be particularly useful for programs that direct-mail FIT kits to patients' homes, where verbal, provider-delivered instruction is infeasible.

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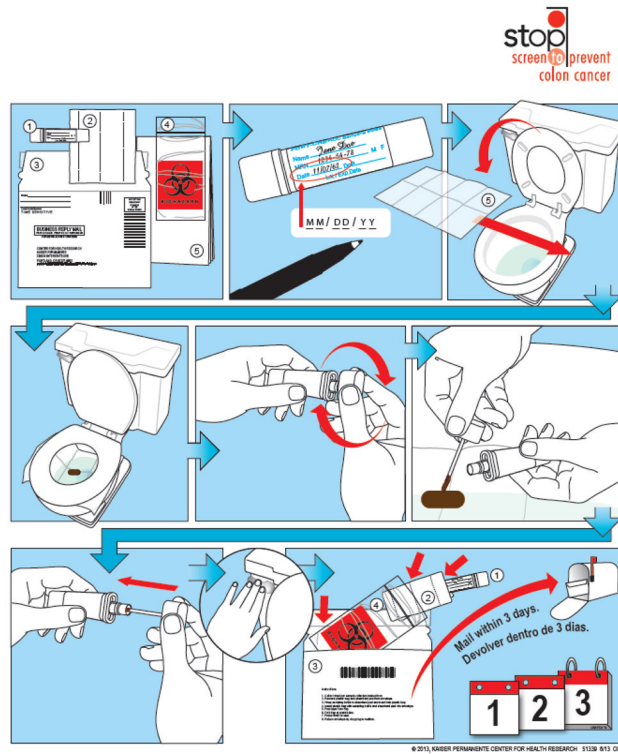


Figure 1.

**Table 1**

Responses from patient advisory council members, clinic staff, and STOP CRC advisory board members

Virginia Garcia Patient Council	Clinic Implementation Team	Advisory Board
<b>Reactions</b>		
<b>Instructions are easy to follow and understandable regardless of reading level.</b>	Preferred the “No Words” instructions because of the ease of looking only at pictures.	It looks great and will appeal to people of all education levels.
Preferred the “No Words” instructions because of the ease of looking only at pictures.		
The image of fecal matter is not offensive or disturbing; it is helpful to know how much is needed for the sample.		
<b>Suggestions</b>		
Modify date to read “MM/DD/13”	Modify date to read “MM/DD/13”	Make it clear that they need to write the date on the bottle.
Color the arrows so they stand out from the base color.	Change the color of the arrows or use bold outline to clearly show the steps.	Label each box with a number so the sequence is clear.
Add a picture that shows all the materials included in the envelope.		
Add text that says “return immediately” because the 3 days might allow people to procrastinate.	Don’t use “return immediately” because it might scare people.	Add text that says “return within 3 days.”
Add bilingual instructions on the back for those who prefer written instructions.		
Insert an introductory letter or note in the kit to remind patients of the STOP CRC program.		
Show the tissue paper as between the seat and toilet bowl.	Toilet seat should be up in order to show that the paper floats on the water.	
	Remove clinic phone numbers to minimize text and make them general use.	
	Remove smiley face and big question mark.	