Health literacy, shared decision making and health inequalities – what do we know and what can we do better?

Marie-Anne Durand **MSc MPhil PhD CPsychol**

Inserm-UMR1295 CERPOP (Inserm-UPS) Équipe EQUITY - Embodiment*inégalités sociales*épidémiologie de la vie*cancer et maladies chroniques*interventions*méthodologie

Inserm
La science pour la santé
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DARTMOUTH

CONFLICTS OF INTERESTS

Financial

Marie-Anne Durand has developed the Option Grid™ patient decision aids, which are licensed to EBSCO Health. She receives consulting income from EBSCO Health and royalties.

Non-financial

Marie-Anne Durand has developed measures of shared decision making.

ACKNOWLEDGEMENTS

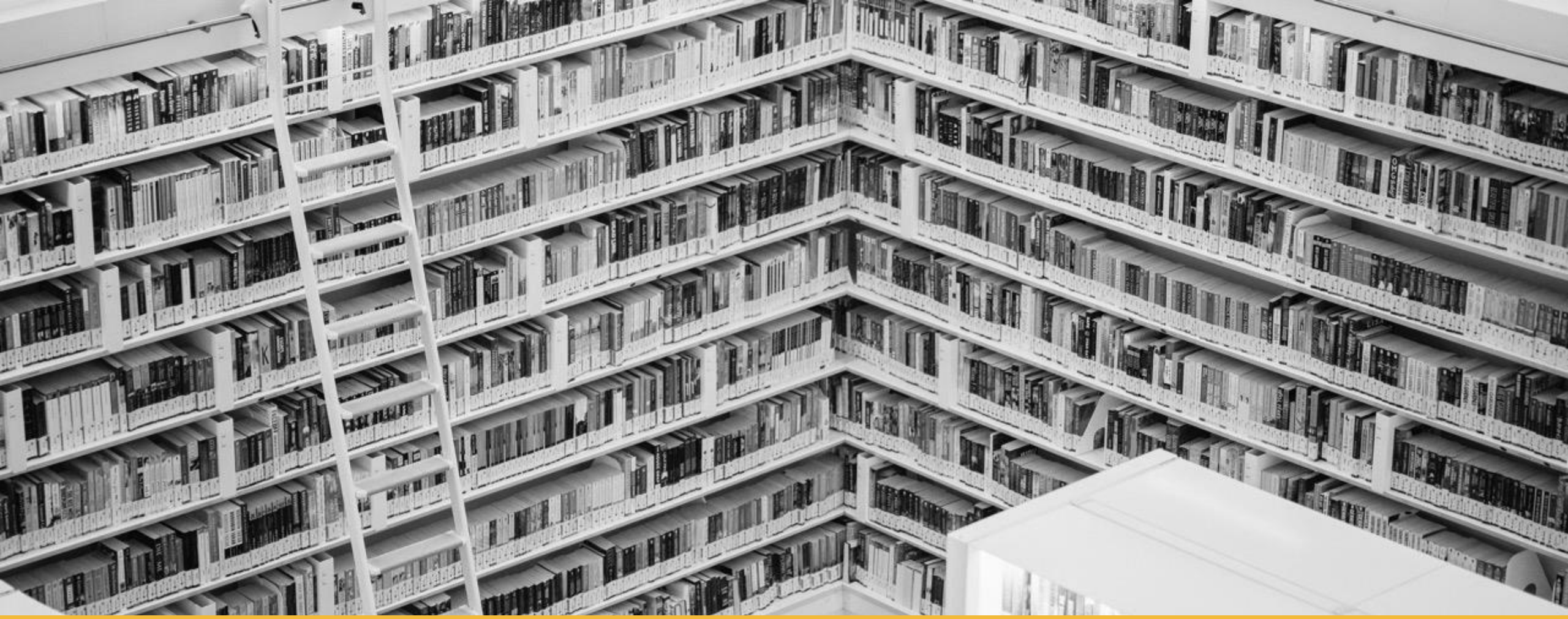
UMR 1295 Team EQUITY, Unisanté in Lausanne, Coproduction Laboratory at Dartmouth College, UMR 1252 SESSTIM, IMéRA, our patient and stakeholder partners and many others…

…

DEFINING HEALTH INEQUALITIES

Health inequalities can be defined as ”the systematic, avoidable and unfair differences in health outcomes that can be observed between populations, between social groups within the same population or as a gradient across a population ranked by social position.”

McCartney G, Popham F, McMaster R, Cumbers A. Defining health and health inequalities. Public Health. 2019 May 30, 172: 22-30.



WHAT DO WE KNOW ALREADY?

Socially disadvantaged patients (including those with lower health literacy) are less likely to engage in health care and to participate in medical decision making.

Evidence suggests that younger patients, women and those with higher socioeconomic status are more likely to play an active role in shared medical decision making.

OPEN ACCESS Freely available online

PLOS ONE

Do Interventions Designed to Support Shared Decision-Making Reduce Health Inequalities? A Systematic Review and Meta-Analysis

Marie-Anne Durand[1]*, Lewis Carpenter[2], Hayley Dolan[1], Paulina Bravo[3], Mala Mann[3], Frances Bunn[4], Glyn Elwyn[5]

1 Centre for Lifespan and Chronic Illness Research, University of Hertfordshire, Hatfield, United Kingdom, 2 School of Nursing, Pontificia Universidad Católica de Chile, Santiago, Chile, 3 Support Unit for Research Evidence, Cardiff University, Cardiff, United Kingdom, 4 Centre for Research in Primary and Community Care, University of Hertfordshire, Hatfield, United Kingdom, 5 The Dartmouth Center for Health Care Delivery Science, Dartmouth College, Hanover, United States of America

Abstract

Background: Increasing patient engagement in healthcare has become a health policy priority. However, there has been concern that promoting supported shared decision-making could increase health inequalities.

Objective: To evaluate the impact of SDM interventions on disadvantaged groups and health inequalities.

Design: Systematic review and meta-analysis of randomised controlled trials and observational studies.

Data Sources: CINAHL, the Cochrane Register of Controlled Trials, the Cochrane Database of Systematic Reviews, EMBASE, HMIC, MEDLINE, the NHS Economic Evaluation Database, Open SIGLE, PsycINFO and Web of Knowledge were searched from inception until June 2012.

Study Eligibility Criteria: We included all studies, without language restriction, that met the following two criteria: (1) assess the effect of shared decision-making interventions on disadvantaged groups and/or health inequalities, (2) include at least 50% of people from disadvantaged groups, except if a separate analysis was conducted for this group.

Results: We included 19 studies and pooled 10 in a meta-analysis. The meta-analyses showed a moderate positive effect of shared decision-making interventions on disadvantaged patients. The narrative synthesis suggested that, overall, SDM interventions increased knowledge, informed choice, participation in decision-making, decision self-efficacy, preference for collaborative decision making and reduced decisional conflict among disadvantaged patients. Further, 7 out of 19 studies compared the intervention's effect between high and low literacy groups. Overall, SDM interventions seemed to benefit disadvantaged groups (e.g. lower literacy) more than those with higher literacy, education and socioeconomic status. Interventions that were tailored to disadvantaged groups' needs appeared most effective.

Conclusion: Results indicate that shared decision-making interventions significantly improve outcomes for disadvantaged patients. According to the narrative synthesis, SDM interventions may be more beneficial to disadvantaged groups than higher literacy/socioeconomic status patients. However, given the small sample sizes and variety in the intervention types, study design and quality, these findings should be interpreted with caution.

Citation: Durand M-A, Carpenter L, Dolan H, Bravo P, Mann M, et al. (2014) Do Interventions Designed to Support Shared Decision-Making Reduce Health Inequalities? A Systematic Review and Meta-Analysis. PLoS ONE 9(5): e94670. doi:10.1371/journal.pone.0094670

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Competing Interests: The authors have declared that no competing interests exist.

* E-mail: m.durand@herts.ac.uk

Introduction

Increasing patient engagement in healthcare is now considered one of the goals of medicine and a priority on the policy agenda [1,2]. Shared decision-making (SDM) is one of the consultation models advocated to promote patient activation and engagement in healthcare [3,4]. It offers a new paradigm to manage patients' growing demand for healthcare by promoting collaborative decision-making between patients and clinical experts. However, there is a risk that SDM primarily attracts and benefits those who are natural information-seekers, who are educated, empowered and able to advocate for their needs, while marginalising patients who are socially excluded and disadvantaged [5]. The idea has therefore emerged that SDM may increase health inequalities. Research shows that involving patients in their care and listening to their views improves knowledge, decision outcomes, compliance with treatments, and reduces the uptake of elective procedures [6].

Review

MDM Medical Decision Making

Medical Decision Making
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SAGE

A Systematic Review and Meta-Analysis of Patient Decision Aids for Socially Disadvantaged Populations: Update from the International Patient Decision Aid Standards (IDPAS)

Renata W. Yen, Jenna Smith, Jaclyn Engel, Danielle M. Muscat, Sian K. Smith, Julien Mancini, Lilisbeth Perestelo-Pérez, Glyn Elwyn, A. James O'Malley, JoAnna K. Leyenaar, Olivia Mac, Tamara Cadet, Anik Giguère, Ashley J. Housten, Aisha Langford, Kirsten McCaffery, and Marie-Anne Durand

Background. The effectiveness of patient decision aids (PtDAs) and other shared decision-making (SDM) interventions for socially disadvantaged populations has not been well studied. **Purpose.** To assess whether PtDAs and other SDM interventions improve outcomes or decrease health inequalities among socially disadvantaged populations and determine the critical features of successful interventions. **Data Sources.** MEDLINE, CINAHL, Cochrane, PsycINFO, and Web of Science from inception to October 2019. Cochrane systematic reviews on PtDAs. **Study Selection.** Randomized controlled trials of PtDAs and SDM interventions that included socially disadvantaged populations. **Data Extraction.** Independent double data extraction using a standardized form and the Template for Intervention Description and Replication checklist. **Data Synthesis.** Twenty-five PtDA and 13 other SDM intervention trials met our inclusion criteria. Compared with usual care, PtDAs improved knowledge (mean difference = 13.91, 95% confidence interval [CI] 9.01, 18.82 [I^2 = 96%]) and patient-clinician communication (relative risk = 1.62, 95% CI 1.42, 1.84 [I^2 = 0%]). PtDAs reduced decisional conflict (mean difference = −9.59; 95% CI −18.94, −0.24 [I^2 = 84%]) and the proportion undecided (relative risk = 0.39; 95% CI 0.28, 0.53 [I^2 = 75%]). PtDAs did not affect anxiety (standardized mean difference = 0.02, 95% CI −0.22, 0.26 [I^2 = 70%]). Only 1 trial looked at clinical outcomes (hemoglobin A1C). Five of the 12 PtDA studies that compared outcomes by disadvantaged standing found that outcomes improved more for socially disadvantaged participants. No evidence indicated which intervention characteristics were most effective. Results were similar for SDM intervention trials. **Limitations.** Sixteen PtDA st
overall unclear risk of bias. Heterogeneity was high for most outcomes. Most studies only had short-ter
Conclusions. PtDAs led to better outcomes among socially disadvantaged populations but did not r
inequalities. We could not determine which intervention features were most effective.

Highlights

- Systematic review and meta-analysis of patient decision aids and other shared decision-making (S
ventions for socially disadvantaged populations.
- Patient decision aids and other SDM interventions improve patient-reported outcomes for socially
taged populations.
- There was no evidence on what intervention characteristics best supported socially disadvantaged p

Corresponding Author
Marie-Anne Durand, The Dartmouth Institute for Hea
Clinical Practice, Dartmouth College, Lebanon, NH, U
anne.durand@dartmouth.edu).

METHODS

Systematic review 1, 2014

- **Purpose:** To evaluate the impact of SDM interventions on disadvantaged groups and health inequalities.
- **Data sources**: CINAHL, the Cochrane Register of Controlled Trials, the Cochrane Database of Systematic Reviews, EMBASE, HMIC, MEDLINE, the NHS Economic Evaluation Database, Open SIGLE, PsycINFO and Web of Knowledge were searched from inception until June 2012.

IPDAS update review, 2021

- **Purpose:** To assess whether PtDAs and SDM interventions improve outcomes or decrease health inequalities among socially disadvantaged populations and determine the critical features of successful interventions.
- **Data sources**: MEDLINE, CINAHL, Cochrane, PsycINFO, and Web of Science from inception to October 2019. Cochrane systematic reviews on PtDAs.

METHODS

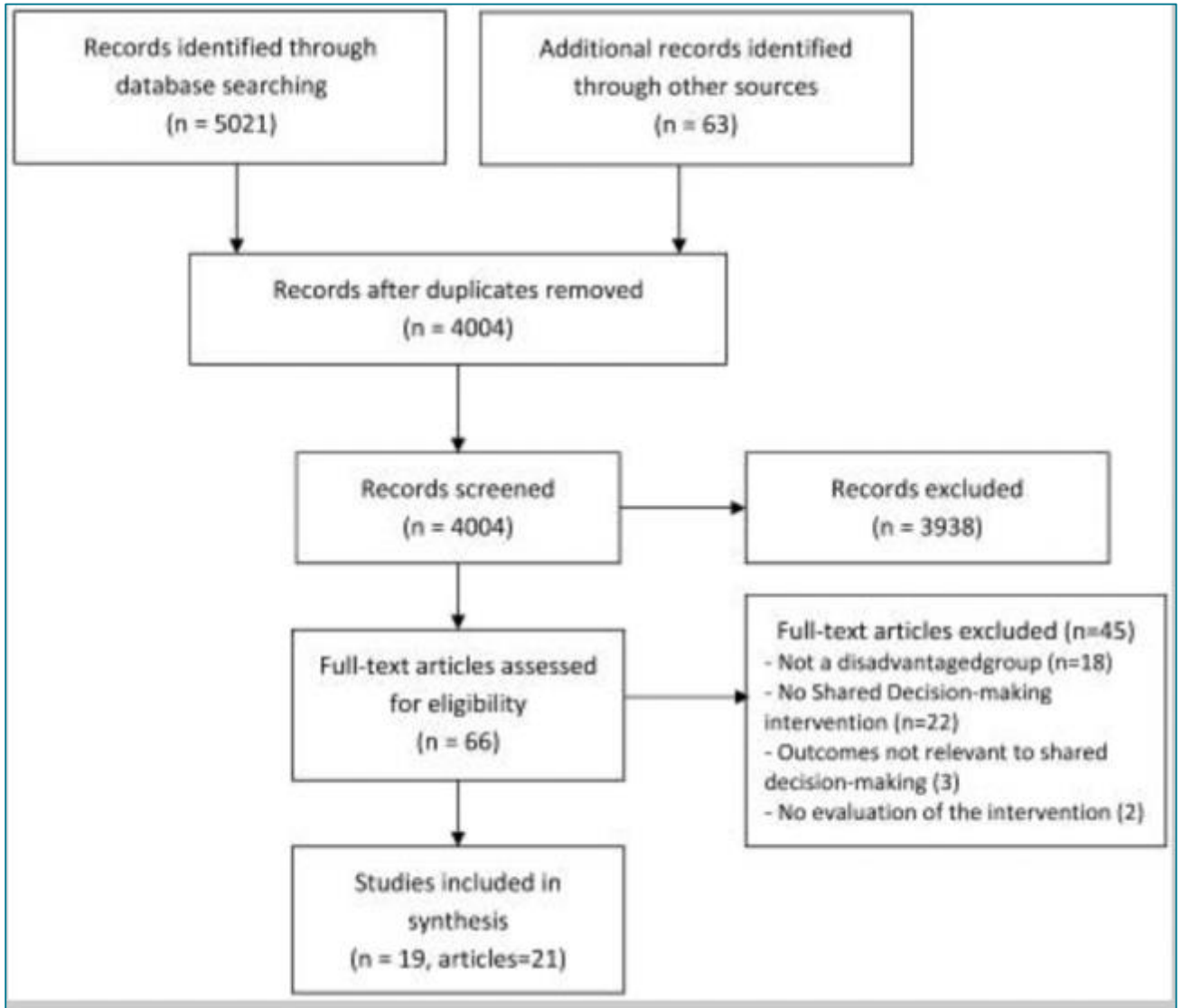
Systematic review 1, 2014

- **Study selection**: All studies without language restriction that assessed the effect of shared decision-making interventions on disadvantaged groups and/or health inequalities
- **Data extraction:** Independent double data extraction using a pre-designed form adapted from an earlier systematic review, and piloted prior to data extraction.
- **Quality assessment:** Cochrane risk of bias tool and Downs & Black checklist.

IPDAS update review, 2021

- **Study selection**: Randomized controlled trials of PtDAs and SDM interventions that included socially disadvantaged populations. No language restrictions.
- **Data extraction:** Independent double data extraction using a standardized form and the Template for Intervention Description and Replication checklist.
- **Quality assessment:** Cochrane risk of bias tool version 2.

RESULTS OF 2014 REVIEW



RESULTS OF 2014 REVIEW

- SDM interventions **improved outcomes for socially disadvantaged populations**: **improved knowledge, improved patient-clinician communication, reduced decisional conflict, reduced the proportion undecided.**

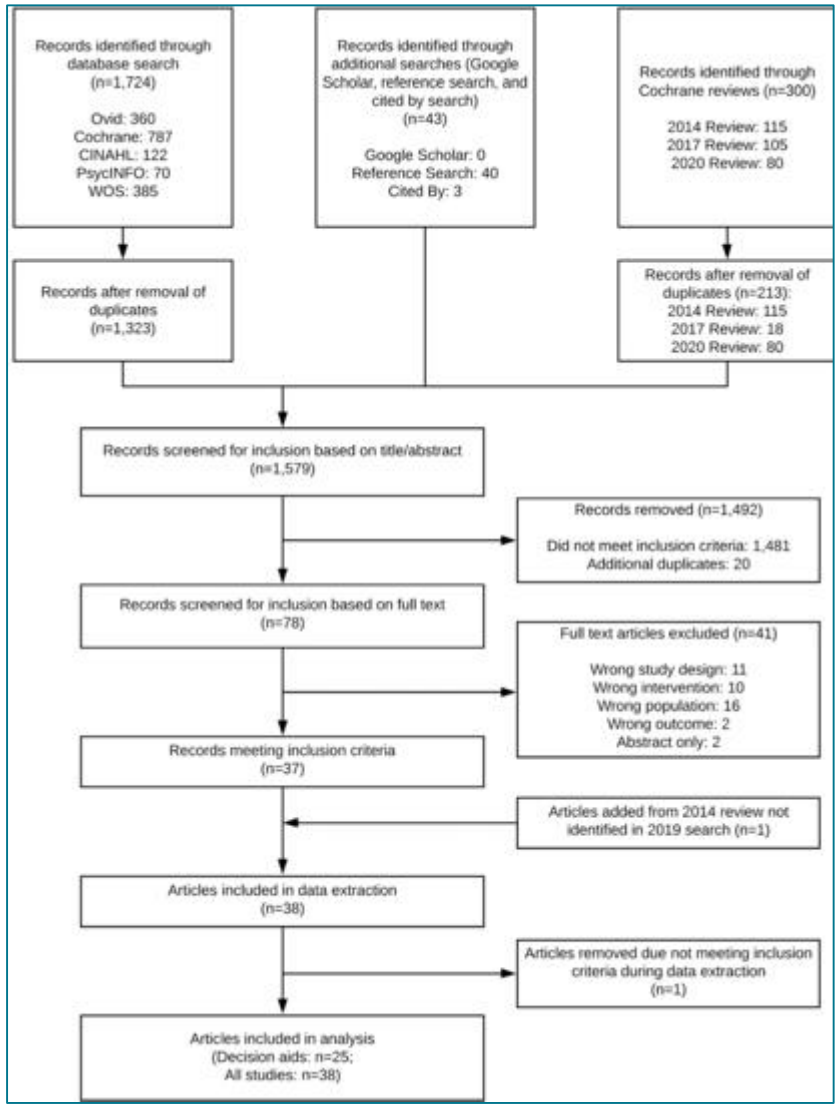
- The narrative synthesis review suggested that SDM interventions may be more beneficial to disadvantaged groups than higher literacy/socioeconomic status patients.

- Tailoring the interventions to disadvantaged groups' needs seemed important.

LIMITATIONS

- Given the paucity of controlled research in this area in 2012 and before, inclusion of all study designs, introducing significant heterogeneity.
- Only 10 included studies could be pooled in the meta-analysis
- The quality of included studies was variable and fairly low.
- Sample size was generally small and follow-up was not systematic and limited.

RESULTS OF 2021 REVIEW



RESULTS OF 2021 REVIEW

- Patient decision aids and other SDM interventions **improved outcomes for socially disadvantaged populations**: **improved knowledge, improved patient-clinician communication, reduced decisional conflict, reduced the proportion undecided.**

- PtDAs did not affect anxiety.

- Five of the 12 PtDA studies that compared outcomes by disadvantaged standing found that outcomes improved more for socially disadvantaged participants.

- No evidence indicated which intervention characteristics were most effective.

LIMITATIONS

- Analysis limited to randomized controlled trials
- Multiple complex definitions of social disadvantage
- Large number of studies with overall unclear risk of bias
- Substantial heterogeneity for most outcomes

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Review Article

Using pictures to convey health information: A systematic review and meta-analysis of the effects on patient and consumer health behaviors and outcomes

Danielle Schubbe[a], Peter Scalia[a], Renata W. Yen[a], Catherine H. Saunders[a], Sarah Cohen[b], Glyn Elwyn[a], Maria van den Muijsenbergh[c,d], Marie-Anne Durand[a,*]

[a] The Dartmouth Institute for Health Policy & Clinical Practice, 1 Medical Center Drive (WTRR, Level 5), Lebanon, NH 03756, USA
[b] Dartmouth College, Hanover, NH 03755, USA
[c] Radboudumc University Medical Center, Nijmegen, The Netherlands
[d] Pharos, Center of Expertise on Health Disparities, Utrecht, The Netherlands

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Health literacy

ABSTRACT

Objective: Assess the effect of pictorial health information on patients' and consumers' health behaviors and outcomes, evaluate these effects in lower health literacy populations, and examine the attributes of the interventions.

Methods: We included randomized controlled trials (RCTs) that assessed the effect of pictorial health information on patient and consumer health behaviors and outcomes. We conducted a meta-analysis of RCTs that assessed knowledge/understanding, recall, or adherence, and a subgroup analysis of those outcomes on lower health literacy populations. We narratively reviewed characteristics of pictorial health interventions that significantly improved outcomes for lower health literacy populations.

Results: From 4160 records, we included 54 RCTs (42 in meta-analysis). Pictorial health information moderately improved knowledge/understanding and recall overall, but largely increased knowledge/understanding for lower health literacy populations (n = 13), all with substantial heterogeneity. Icons with few words may be most helpful in conveying health information.

Conclusion: Our results support including pictures in health communication to improve patient knowledge. Our results should be interpreted with c
the meta-analysis outcomes.

Practice implications: Future research should assess wh
health information and are most useful and the implem

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Contents

* Corresponding author.
E-mail address: marie-anne.durand@dartmouth.edu (M.-A. Durand).

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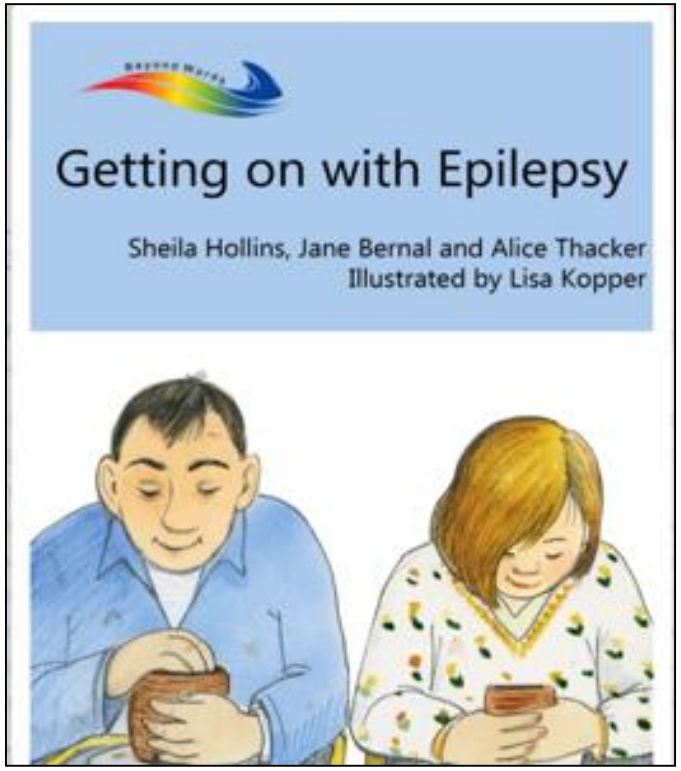

METHODS

- **Purpose:** Assess the effect of pictorial health information on patients' and consumers' health behaviors and outcomes, evaluate these effects in lower health literacy populations, and examine the attributes of the interventions.
- **Data sources:** Ovid MEDLINE, PsycINFO, Web of Science, CINAHL, Cochrane Database of Systematic reviews, Cochrane Central Register of Controlled Trials, Cochrane Methodology Register, Database of Abstracts and Reviews of Effectiveness, and ERIC from inception until August 2018 + eight additional search strategies.
- **Study selection**: RCTs that assessed the effect of pictorial health information on patient and consumer health behaviors and outcomes. No language restrictions.
- **Data extraction:** Independent dual data extraction with pre-designed, piloted form adapted from: 1) the Cochrane Effective Practice and Organization of Care (EPOC) checklist and 2) TIDieR checklist for characteristics of the pictorial health interventions.
- **Quality assessment:** Cochrane risk of bias tool.

RESULTS

- We screened the titles and abstracts of 4176 unique articles, assessed the full text of 250 articles, and found 54 articles that met all inclusion criteria. **The 54 included RCTs were conducted across 22 countries between 1990 and 2017.**

- Pictorial health information moderately improved knowledge/understanding and recall overall, but largely increased knowledge/ understanding for lower health literacy populations (n = 13), all with substantial heterogeneity.

- Icons with few words may be most helpful in conveying health information.

LIMITATIONS

- Analysis limited to randomized controlled trials.
- Not all authors reported the details of their interventions or study characteristics, which prevented a thorough review of all intervention characteristics and risk of bias assessment.
- Heterogeneity of the meta-analysis results.

WHAT MATTERS MOST

Original Article

What Matters Most: Randomized Controlled Trial of Breast Cancer Surgery Conversation Aids Across Socioeconomic Strata

Marie-Anne Durand, PhD[1,2]; Renata W. Yen, MPH[3]; A. James O'Malley, PhD[1,3]; Danielle Schubbe, BA[1]; Mary C. Politi, PhD[4]; Catherine H. Saunders, PhD[1,5]; Shubhada Dhage, MD[6]; Kari Rosenkranz, MD[3]; Julie Margenthaler, MD[4]; Anna N. A. Tosteson, ScD[1,7]; Eloise Crayton, BSN, RN, MA[4]; Sherrill Jackson, NP, MHA[4]; Ann Bradley, BSN, RN, MEd[3]; Linda Walling, AA[1]; Christine M. Marx, MA[4]; Robert J. Volk, PhD[8]; Karen Sepucha, PhD[9]; Elissa Ozanne, PhD[10]; Sanja Percac-Lima, MD, PhD[11]; Emily Bergin, MS[12]; Courtney Goodwin, MPH[4]; Caity Miller, BSC[12]; Camille Harris, MPH[1]; Richard J. Barth, Jr, MD[3]; Rebecca Aft, MD[4]; Sheldon Feldman, MD[12]; Amy E. Cyr, MD[4]; Christina V. Angeles, MD[3]; Shuai Jiang, MS[13]; and Glyn Elwyn, MB, BCh, PhD[1]

BACKGROUND: Women of lower socioeconomic status (SES) with early-stage breast cancer are more likely to report poorer physician-patient communication, lower satisfaction with surgery, lower involvement in decision making, and higher decision regret compared to women of higher SES. The objective of this study was to understand how to support women across socioeconomic strata in making breast cancer surgery choices. **METHODS:** We conducted a 3-arm (Option Grid, Picture Option Grid, and usual care), multisite, randomized controlled superiority trial with surgeon-level randomization. The Option Grid (text only) and Picture Option Grid (pictures plus text) conversation aids were evidence-based summaries of available breast cancer surgery options on paper. Decision quality (primary outcome), treatment choice, treatment intention, shared decision making (SDM), anxiety, quality of life, decision regret, and coordination of care were measured from T0 (pre-consultation) to T5 (1-year after surgery). **RESULTS:** Sixteen surgeons saw 571 of 622 consented patients. Patients in the Picture Option Grid arm (n = 248) had higher knowledge (immediately after the visit [T2] and 1 week after surgery or within 2 weeks of the first postoperative visit [T3]), an improved decision process (T2 and T3), lower decision regret (T3), and more SDM (observed and self-reported) compared to usual care (n = 257). Patients in the Option Grid arm (n = 66) had higher decision process scores (T2 and T3), better coordination of care (12 weeks after surgery or within 2 weeks of the second postoperative visit [T4]), and more observed SDM (during the surgical visit [T1]) compared to usual care arm. Subgroup analyses suggested that the Picture Option Grid had more impact among women of lower SES and health literacy. Neither intervention affected concordance, treatment choice, or anxiety. **CONCLUSIONS:** Paper-based conversation aids improved key outcomes over usual care. The Picture Option Grid had more impact among disadvantaged patients. **Cancer 2021;127:422-438.** © 2020 The Authors. Cancer published by Wiley Periodicals LLC on behalf of American Cancer Society This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

LAY SUMMARY:

- The objective of this study was to understand how to help women with lower incomes or less formal education to make breast cancer surgery choices.
- Compared with usual care, a conversation aid with pictures and text led to higher knowledge. It improved the decision process and shared decision making (SDM) and lowered decision regret. A text-only conversation aid led to an improved decision process, more coordinated care, and higher SDM compared to usual care. The conversation aid with pictures was more helpful for women with lower income or less formal education.
- Conversation aids with pictures and text helped women make better breast cancer surgery choices.

KEYWORDS: breast cancer disparities, breast cancer surgery, conversation aids, decision support techniques, lower educational attainment, lower health literacy, lower socioeconomic status, pictorial superiority.

Corresponding Author: Marie-Anne Durand, PhD, Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth College, 1 Medical Center Dr, Lebanon, NH 03766 (marie-anne.durand@dartmouth.edu).

[1]Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth College, Lebanon, New Hampshire; [2]UMR 1027 Team EQUITY, Paul Sabatier University, Toulouse, France; [3]Department of Biomedical Data Science, Geisel School of Medicine at Dartmouth, Lebanon, New Hampshire; [4]Department of Surgery, Washington University School of Medicine, St. Louis, Missouri; [5]Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire; [6]Laura and Isaac Perlmutter Cancer Center, New York University School of Medicine, New York, New York; [7]Norris Cotton Cancer Center, Lebanon, New Hampshire; [8]The University of Texas MD Anderson Cancer Center, Houston, Texas; [9]Division of General Internal Medicine, Massachusetts General Hospital, Boston, Massachusetts; [10]Department of Population Health Sciences, School of Medicine, University of Utah, Salt Lake City, Utah; [11]Massachusetts General Hospital Chelsea HealthCare Center, Chelsea, Massachusetts; [12]Montefiore Medical Center, Bronx, New York

This trial is registered at ClinicalTrials.gov (NCT03136367).

Additional supporting information may be found in the online version of this article.

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USUAL CARE

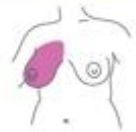
Early-Stage Breast Cancer Treatment Options

picture option grid

This decision aid is for people with early-stage breast cancer who are considering lumpectomy with radiation or mastectomy. It is not for people with inflammatory or late-stage breast cancer. Another decision aid is available for breast reconstruction after mastectomy.

About Early-Stage Breast Cancer: This means cancer cells are only in the breast and possibly in the armpit.

What does the option involve?

Lumpectomy with Radiation	Mastectomy
	
You will have surgery to remove the cancer and some tissue around it. You may need another surgery if signs of cancer are on the edges of the removed tissue. You may go home the same day. After you heal, you will get radiation 5 days a week for 3 to 6 weeks.	You will have surgery to remove the whole breast. You may be in the hospital for at least 1 day. Tubes will be left under the skin for up to 2 weeks to help you heal.

What about these treatment options is the same?

Lumpectomy with Radiation	Mastectomy
	

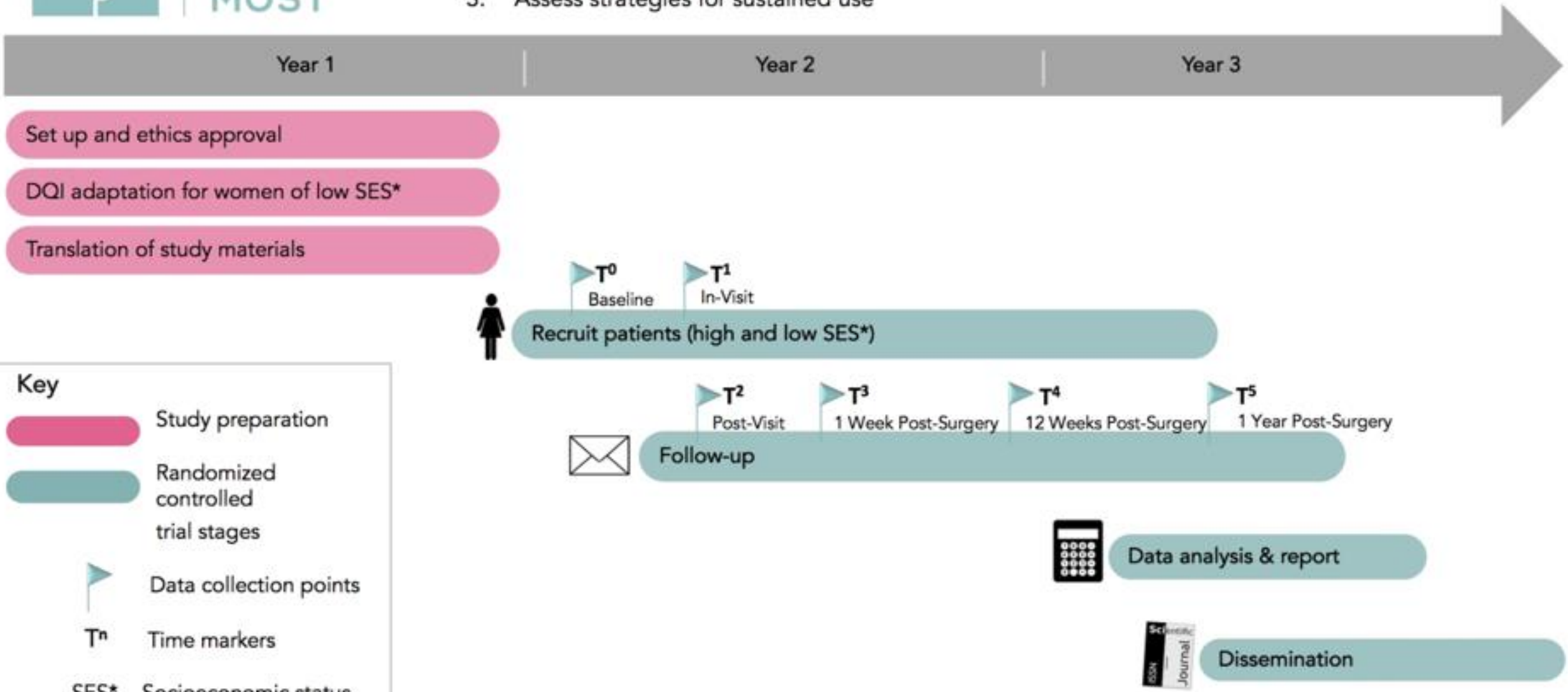
No matter which treatment you choose:

- You may need other treatments like **radiation, hormone therapy, or chemotherapy.**
- Some lymph nodes in your armpit will be removed for testing.

WHAT MATTERS MOST

Study Aims

1. Assess comparative effectiveness of Option Grid and Picture Option Grid against usual care
2. Measure the effect of Picture Option Grid on disparities
3. Assess strategies for sustained use



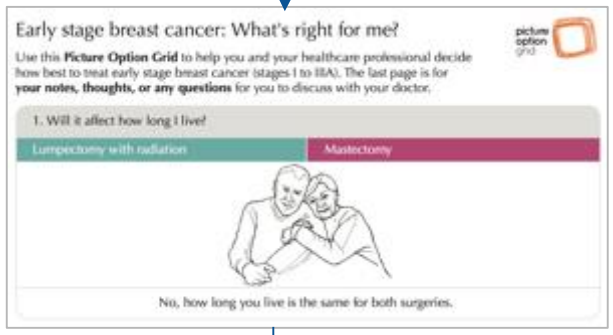
STUDY FLOW

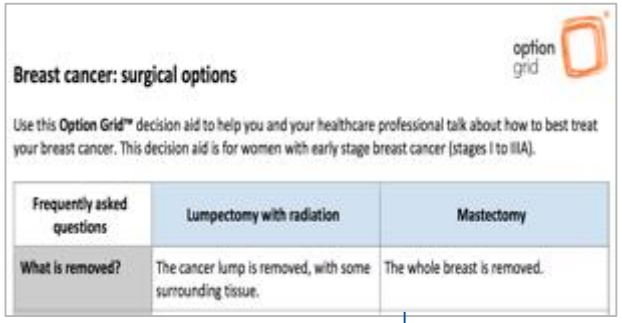
Screened

Baseline assessment

Randomization
(surgeon-level)

Picture Option Grid | **Usual care** | **Option Grid**





Follow-Ups: **After** consultation, **1 week** post-surgery, **12 weeks** post-surgery, **1 year** post-surgery

OPTION GRID

- ✓ Increases observed shared decision making (estimate: 28.93, 95% CI (7.98, 49.87), P=.01)
- ✓ Increases self-reported shared decision making (estimate: 1.18, 95% CI (0.23, 2.13), P=.02)
- ✓ Increases care coordination (estimate: 0.66, 95% CI (0.04, 1.28), P=.04)

option grid

Breast cancer: surgical options

Use this **Option Grid™** decision aid to help you and your healthcare professional talk about how to best treat your breast cancer. This decision aid is for women with early stage breast cancer (stages I to IIIA).

Frequently asked questions	Lumpectomy with radiation	Mastectomy
What is removed?	The cancer lump is removed, with some surrounding tissue.	The whole breast is removed.
Which surgery is best for long-term survival?	Long-term survival rates are the same for both surgeries.	Long-term survival rates are the same for both surgeries.
What are the chances of cancer coming back in the breast?	Breast cancer will come back in the breast in about 5 to 10 in 100 women (5-10%) in the 10 years after a lumpectomy.	Breast cancer will come back in the area of the scar in about 5 to 10 in 100 women (5-10%) in the 10 years after a mastectomy.
Will I need more than one surgery?	Possibly, 20 in 100 women (20%) may need another surgery to remove breast tissue or lymph node that have cancer.	Possibly, if your lymph nodes have cancer. Yes, if you choose breast reconstruction.
How long will it take to recover?	Most women are home within 24 hours of surgery.	Most women are home within 24 hours of surgery. It may take longer with reconstruction.
Will I need radiation after surgery?	Yes, for up to seven weeks after surgery.	Radiation is not usually given after mastectomy.
Will my lymph nodes be removed?	If cancer has spread to the lymph nodes under your arm, your doctor will discuss with you whether you need more treatment such as surgery or radiotherapy.	If cancer has spread to the lymph nodes under your arm, your doctor will discuss with you whether you need more treatment such as surgery or radiotherapy.
Will I need chemotherapy?	You may be offered chemotherapy, but this does not depend on the surgery you choose.	You may be offered chemotherapy, but this does not depend on the surgery you choose.
Will I lose my hair?	Hair loss is common after chemotherapy.	Hair loss is common after chemotherapy.

Editors: Marie-Anne Durand (Lead Editor), Glyn Elwyn, Lisa Caldon, Karl Rosenkranz, Dale Collins Vidal, Stephanie Sivell, Malcolm Reed
Evidence document: http://optiongrid.org/admin/resources/grid/evidences/9.pdf?x=WBZ1nd4YE

Publication date: 23 August 2017 Expiry date: 23 August 2019

PICTURE OPTION GRID

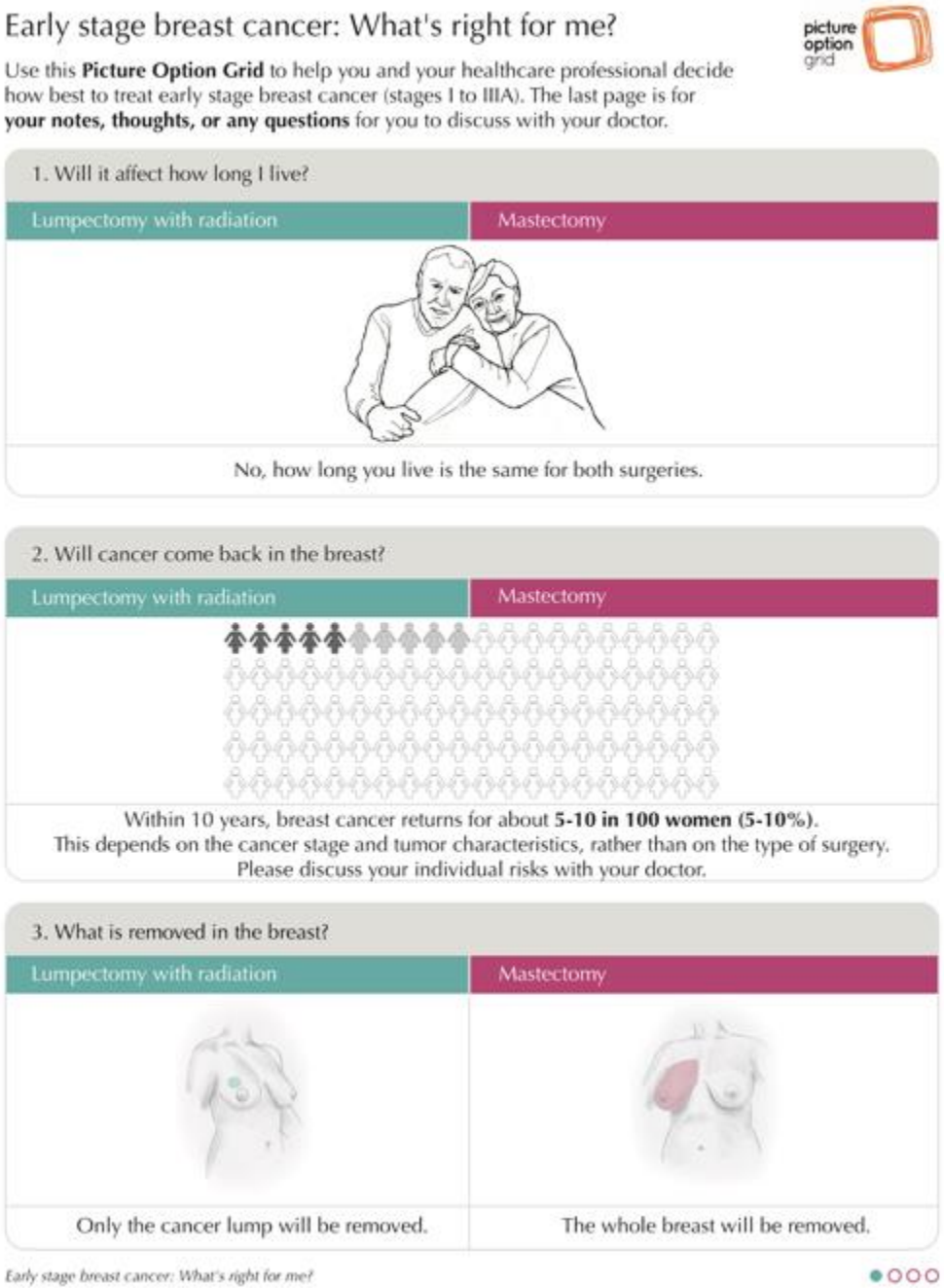
- ✓ Increases knowledge
(estimate: 0.27, 95% CI (0.01, 0.53), P=.04)

- ✓ Increases decision process

- ✓ Increases self-reported shared decision making
(estimate: 0.17, 95% CI (0.03, 0.32), P=.01)

- ✓ Increases observed shared decision making
(estimate: 24.71, 95% CI (5.93, 43.49), P=.01)

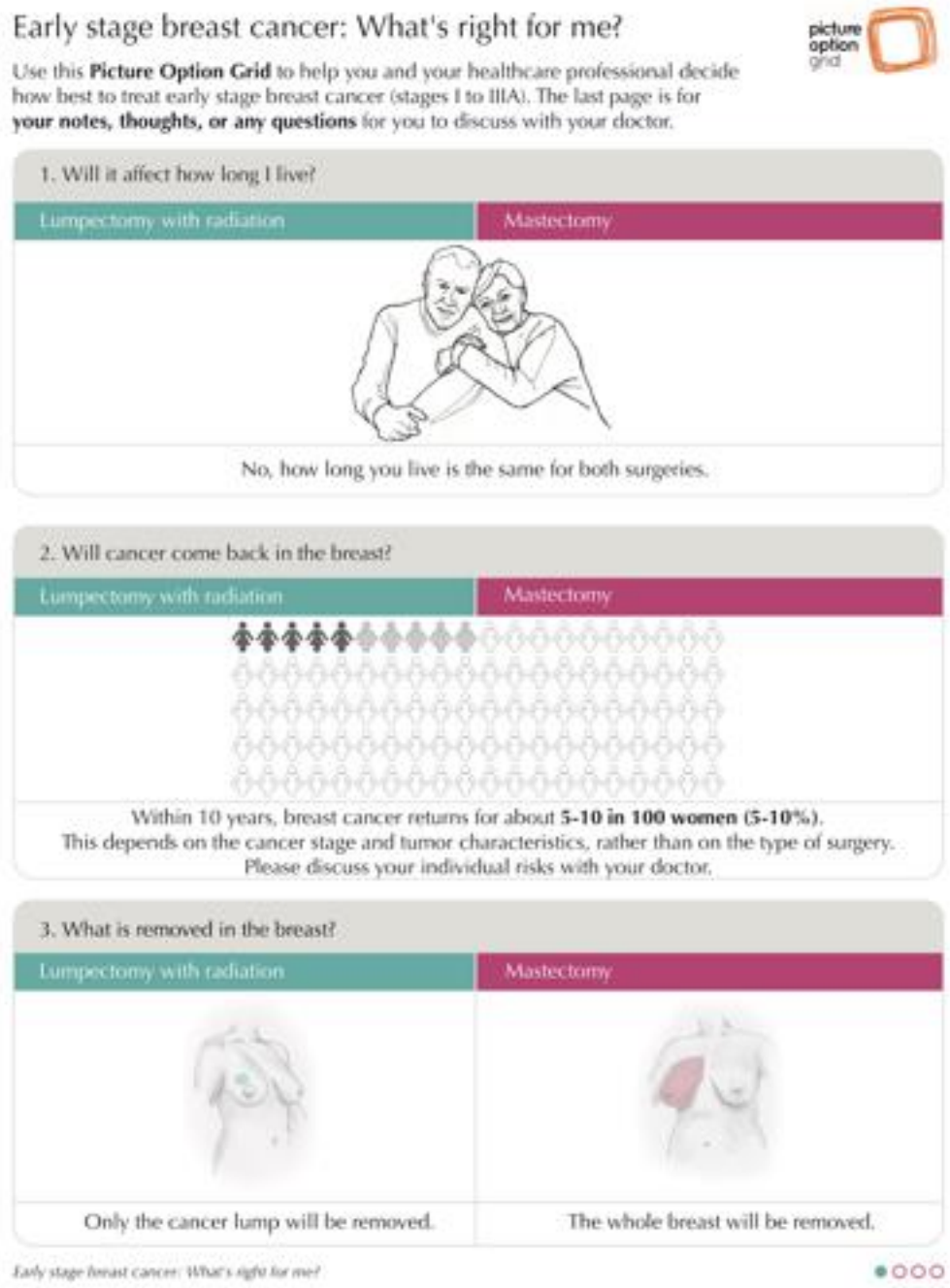
- ✓ Reduces decision regret (T3)
(estimate: -23.16, 95%CI (-45.28, -1.04), P=.04).



SUBGROUP ANALYSES

- ✓ The difference in quality of life between patients of higher health literacy and patients of lower health literacy was smaller in the Picture Option Grid arm than the usual-care arm.
  (estimate: 0,05, IC à 95% (0,01, 0,09), P = .03)

- ✓ The difference in knowledge between patients of lower socioeconomic position (SEP) and those of higher SEP was smaller for patients in the Picture Option Grid arm than patients in the usual-care arm.
  (estimate, 0.36; 95% CI, 0.09-0.63; P = .01)



LIMITATIONS

- Randomization at surgeon level led to imbalance of arms.
- Lower than expected number of eligible patients.
- Attrition of the number of eligible patients between T0 and T3 occurred as patients became ineligible after additional examinations revealed that their stage or surgical options had changed.
- Difficulties recruiting women of lower socioeconomic position.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JOURNAL OF CLINICAL ONCOLOGY ORIGINAL REPORT

Health Care Provider–Directed Intervention to Increase Colorectal Cancer Screening Among Veterans: Results of a Randomized Controlled Trial

M. Rosario Ferreira, Nancy C. Dolan, Marian L. Fitzgibbon, Terry C. Davis, Nicolle Gorby, Lisa Ladewski, Dachao Liu, Alfred W. Rademaker, Franklin Medio, Brian P. Schmitt, and Charles L. Bennett

From the Veterans Affairs Midwest Center for Health Services and Policy Research, Hines; Veterans Affairs Chicago Health Care System; Departments of Medicine, Psychiatry, and Preventive Medicine, Center for Healthcare Studies, and Robert H. Lurie Comprehensive Cancer Center, Feinberg School of Medicine, Northwestern University, Chicago, IL; Louisiana State University Health Sciences Center–Shreveport, Shreveport, LA; and Medical University of South Carolina, Charleston, SC.

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Authors' disclosures of potential conflicts of interest are found at the end of this article.

Address reprint requests to M. Rosario Ferreira, MD, MAPP, 676 N St Clair St, Ste 1400, Chicago, IL 60611; e-mail: mr-ferreira@northwestern.edu.

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DOI: 10.1200/JCO.2005.07.049

ABSTRACT

Purpose
Colorectal cancer screening is the most underused cancer screening tool in the United States. The purpose of this study was to test whether a health care provider–directed intervention increased colorectal cancer screening rates.

Patients and Methods
The study was a randomized controlled trial conducted at two clinic firms at a Veterans Affairs Medical Center. The records of 5,711 patients were reviewed; 1,978 patients were eligible. Eligible patients were men aged 50 years and older who had no personal or family history of colorectal cancer or polyps, had not received colorectal cancer screening, and had at least one visit to the clinic during the study period. Health care providers in the intervention firm attended a workshop on colorectal cancer screening. Every 4 to 6 months, they attended quality improvement workshops where they received group screening rates, individualized confidential feedback, and training on improving communication with patients with limited literacy skills. Medical records were reviewed for colorectal cancer screening recommendations and completion. Literacy level was assessed in a subset of patients.

Results
Colorectal cancer screening was recommended for 76.0% of patients in the intervention firm and for 69.4% of controls ($P = .02$). Screening tests were completed by 41.3% of patients in the intervention group versus 32.4% of controls ($P = .003$). Among patients with health literacy skills less than ninth grade, screening was completed by 55.7% of patients in the intervention group versus 30% of controls ($P < .01$).

Conclusion
A provider-directed intervention with feedback on individual and firm-specific screening rates significantly increased both recommendations and colorectal cancer screening completion rates among veterans.

J Clin Oncol 23:1548-1554. © 2005 by American Society of Clinical Oncology

INTRODUCTION

Colorectal cancer is the third most common cancer and the third most common cause of cancer-related deaths among men in the United States.[1] In 2004, an estimated 146,940 persons will be diagnosed with colorectal cancer in the United States, and 56,730 patients will die of the disease.[1] Colorectal cancer screening with fecal occult blood testing (FOBT) or flexible sigmoidoscopy reduces colorectal cancer–related mortality.[2-7] Although colorectal cancer screening is recommended for individuals 50 years and older,[8-10] screening is underused. In a national population-based survey conducted in 2001, only 23.5% of respondents reported having a FOBT in the preceding year, and 38.7%

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BMC Public Health

STUDY PROTOCOL Open Access

Impact of a health literacy intervention combining general practitioner training and a consumer facing intervention to improve colorectal cancer screening in underserved areas: protocol for a multicentric cluster randomized controlled trial

Marie-Anne Durand[1,2,3], Aurore Lamouroux[4,5], Niamh M. Redmond[1*], Michel Rotily[4,6], Aurélie Bourmaud[7], Anne-Marie Schott[8], Isabelle Auger-Aubin[9], Adèle Frachon[9], Catherine Exbrayat[10], Christian Balamou[10], Laëtitia Gimenez[1,11], Pascale Grosclaude[1,12], Nora Moumjid[13], Julie Haesebaert[8], Helene Delattre Massy[14], Julia Bardes[14], Rajae Touzani[15,16], Laury Beaubrun en Famille Diant[17], Clémence Casanova[16], Jean François Seitz[18,19], Julien Mancini[16] and Cyrille Delpierre[1]

Abstract

Background: Colorectal cancer (CRC) is a leading cause of cancer burden worldwide. In France, it is the second most common cause of cancer death after lung cancer. Systematic uptake of CRC screening can improve survival rates. However, people with limited health literacy (HL) and lower socioeconomic position rarely participate. Our aim is to assess the impact of an intervention combining HL and CRC screening training for general practitioners (GPs) with a pictorial brochure and video targeting eligible patients, to increase CRC screening and other secondary outcomes, after 1 year, in several underserved geographic areas in France.

* Correspondence: niamh-maria.redmond@univ-tlse3.fr
[1]CERPOP, INSERM UMR1295, Université Toulouse III Paul Sabatier, Inserm, UPS, Toulouse, France
Full list of author information is available at the end of the article

ZONE LOGOTYPE

INSTITUT NATIONAL DU CANCER

Nom de la Lorem Ipsum
Lorem ipsum dolor sit amet
Sit amet
Lorem ipsum dolor sit amet

Madame Marie Dupont
12, rue du Pont
55 120 Exemploville

Exemploville, le 26 juillet 2018

VOUS AVEZ PLUS DE 50 ANS, le dépistage du cancer colorectal vous concerne.
PARLEZ-EN avec votre médecin traitant.

Madame, Monsieur,

À partir de 50 ans, le risque de développer un cancer colorectal est plus fréquent.

Le dépistage, tous les 2 ans, est un moyen efficace de lutter contre ce cancer et de le détecter tôt, permettant ainsi de meilleures chances de guérison. Il est même possible de repérer dans certains cas une lésion précancéreuse et de la soigner avant qu'elle n'évolue en cancer.

Nous vous proposons de bénéficier du programme national de dépistage, que nous organisons en lien avec votre médecin traitant.

Dès votre prochaine consultation, pensez à lui présenter cette lettre. Il vérifiera que vous êtes bien concerné(e) et vous remettra le nouveau test de dépistage.
Ce test, à réaliser chez vous, est pris en charge à 100 % sans avance de frais. Simple, rapide et indolore, il peut vous sauver la vie.

Pour plus d'informations, nous vous invitons à lire le dépliant joint.

Avec toute mon attention,
Dr Dupont, médecin coordonnateur du centre de coordination des dépistages des cancers.

En savoir plus : (numéro de la Structure de gestion) ou e-cancer.fr
N.B. : pour vérifier que vous êtes bien concerné, voir au dos.

Présentez cette lettre et vos étiquettes au médecin lors de la consultation. Elles seront à utiliser lorsque vous ferez le test.

ÉTIQUETTE À SAISIR ET À COLLER SUR LE TUBE

NUMÉRO D'INVITATION

ÉTIQUETTE À COLLER SUR LA FICHE D'IDENTIFICATION

Madame
Dupont Marie
Naissance : 20/03/1960
Nº de Sécurité sociale : 1 55 01 99 458 036 87
12, rue du Pont
55 120 Exemploville
Organisme de rattachement : 01 0123 1234
Nº d'invitation : 55 00125000

S'agissant de l'information relative au traitement de vos données personnelles et à vos droits, voir la mention au verso de ce courrier.

Vous n'êtes pas concerné(e) par ce dépistage dans les cas indiqués ci-dessous.
Merci de remplir et de renvoyer ce questionnaire.

☐ Je ne participe pas au dépistage pour l'une des raisons suivantes :

☐ J'ai fait un test de dépistage pour ce cancer il y a moins de 2 ans :
Date : [J J] [M M] [A A A A]

☐ J'ai une maladie inflammatoire intestinale chronique (rectocolite hémorragique, maladie de Crohn)* ;

☐ Je suis suivi(e) par coloscopie, car il y a dans ma famille des cas de maladies prédisposant au cancer colorectal (polypose adénomateuse familiale, syndrome de Lynch, etc.) ;

☐ Je suis suivi(e) par coloscopie, car dans ma famille, l'un de mes proches (parent, enfant, frère, sœur) a eu un cancer colorectal ou un adénome avancé avant 65 ans ;

☐ Je suis suivi(e) par coloscopie car on m'a diagnostiqué par le passé un cancer du côlon ou du rectum ;

☐ Je suis suivi(e) par coloscopie car on m'a diagnostiqué par le passé un ou des polype(s) ou adénome(s) dans le côlon ou le rectum ;

☐ J'ai eu une coloscopie il y a moins de 5 ans pour un autre motif que ceux qui sont cités ci-dessus :
Date : [J J] [M M] [A A A A]
Motif :

☐ Je dois prochainement réaliser une coloscopie pour un autre motif que ceux qui sont cités ci-dessus :
Date : [J J] [M M] [A A A A]
Motif :

☐ J'ai eu un « coloscanner » il y a moins de 2 ans (quel que soit le motif) :
Date : [J J] [M M] [A A A A]

☐ Je ne souhaite pas participer au dépistage de manière définitive pour une autre raison**.
Merci de préciser :
Date : [J J] [M M] [A A A A] Signature :

Nous vous remercions de retourner ce document complété au [Dr Specimen], médecin coordonnateur de [nom de la SC et adresse et numéro de téléphone]

N'hésitez pas à nous contacter si vous avez des questions sur la façon de répondre à ce questionnaire.

* Un suivi régulier par coloscopie est en général recommandé dans ce cas. Parlez en avec votre médecin.
** Il vous est possible de revenir à tout moment sur votre choix.

Information relative au traitement de vos données personnelles et à vos droits
Au titre de leur mission de service public, les structures en charge de la gestion des dépistages des cancers constituent des fichiers d'invitation à partir d'un traitement de données automatisé et assurent le suivi des personnes concernées par le dépistage. A ces fins, elles recueillent des données concernant votre identité et votre santé auprès des caisses d'assurance maladie et des professionnels de santé concernés. La structure de votre région conservera l'ensemble de vos données jusqu'à la fin de votre suivi. Les données nécessaires à votre suivi médical seront transmises aux professionnels de santé concernés. Les données nécessaires aux évaluations et travaux statistiques seront communiquées aux structures publiques en charge de ces missions, dont l'Institut national du cancer et Santé publique France. Conformément au Règlement général sur la protection des données 2016/679 et à la loi informatique et libertés n°78-17 modifiée, vous disposez d'un droit d'opposition, d'accès, de rectification, d'effacement, d'un droit à la portabilité de vos données et d'un droit à la limitation de leur traitement que vous pouvez exercer pendant la durée du traitement en écrivant à la structure de votre région à l'adresse suivante : [Insérer adresse mail]. Vous trouverez l'ensemble de ses coordonnées, celles de son représentant et celles de son délégué à la protection des données sur son site internet. Un recours peut être introduit auprès de la Commission nationale de l'informatique et des libertés.

À RETENIR SUR LE TEST

Le test peut trouver des petits cancers ou des polypes* qui peuvent devenir un cancer.

90 personnes sur 100 (90%) survivent si un cancer colorectal est trouvé tôt.

Trouvé tôt, ce cancer se soigne plus facilement.

ILS EN PARLENT

" Je peux faire mon test à la maison. Faire le test me rassure.

Jacqueline, 59 ans

DES QUESTIONS SUR LE TEST ?

Parlez-en à votre **docteur**.

Visitez **e-cancer.fr** ou le site de votre centre régional de coordination des dépistages des cancers.

Appelez le numéro gratuit : **0 805 123 124**

Regardez le mode d'emploi en vidéo en utilisant une application QR code sur votre téléphone.

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LE DÉPISTAGE DU CANCER DU CÔLON ET DU RECTUM

Pour les hommes et les femmes de **50 à 74 ans**

Faites ce test

POUR QUI ?

Pour les hommes et les femmes de 50 à 74 ans sans douleur inhabituelle au ventre, ni sang visible dans le caca.

Parlez à votre docteur si vous ou un membre de votre famille a eu un cancer colorectal ou des **polypes***.

*Un polype est comme une petite boule qui pousse dans le gros intestin.

POURQUOI ?

Le cancer du côlon et du rectum apparait lentement dans le gros intestin.

C'est le 2ème cancer le plus mortel.

Le test cherche du sang **caché** dans le caca.

Le test peut trouver des cancers tôt et **sauver des vies.**

BON À SAVOIR

Si vous n'arrivez pas à faire le test, demandez une autre enveloppe.

Le test est rapide et ne fait pas mal.

Pas besoin de timbre, c'est gratuit.

Ne faites pas le test le week-end ou avant un jour férié.

Faites le test tous les 2 ans.

COMMENT ?

1. Votre docteur vous donnera le test.

2. Demandez au docteur de vous expliquer le mode d'emploi.

3. Ecrivez la date du test sur la feuille colorée et collez-y la grande étiquette.

4. Mettez la date du test sur la petite

6. Faites pipi avant de faire caca puis collez la feuille.

7. Ouvrez le tube.

8. Grattez le caca avec la tige pour couvrir le bout.

9. Fermez le tube et secouez.

LE RÉSULTAT

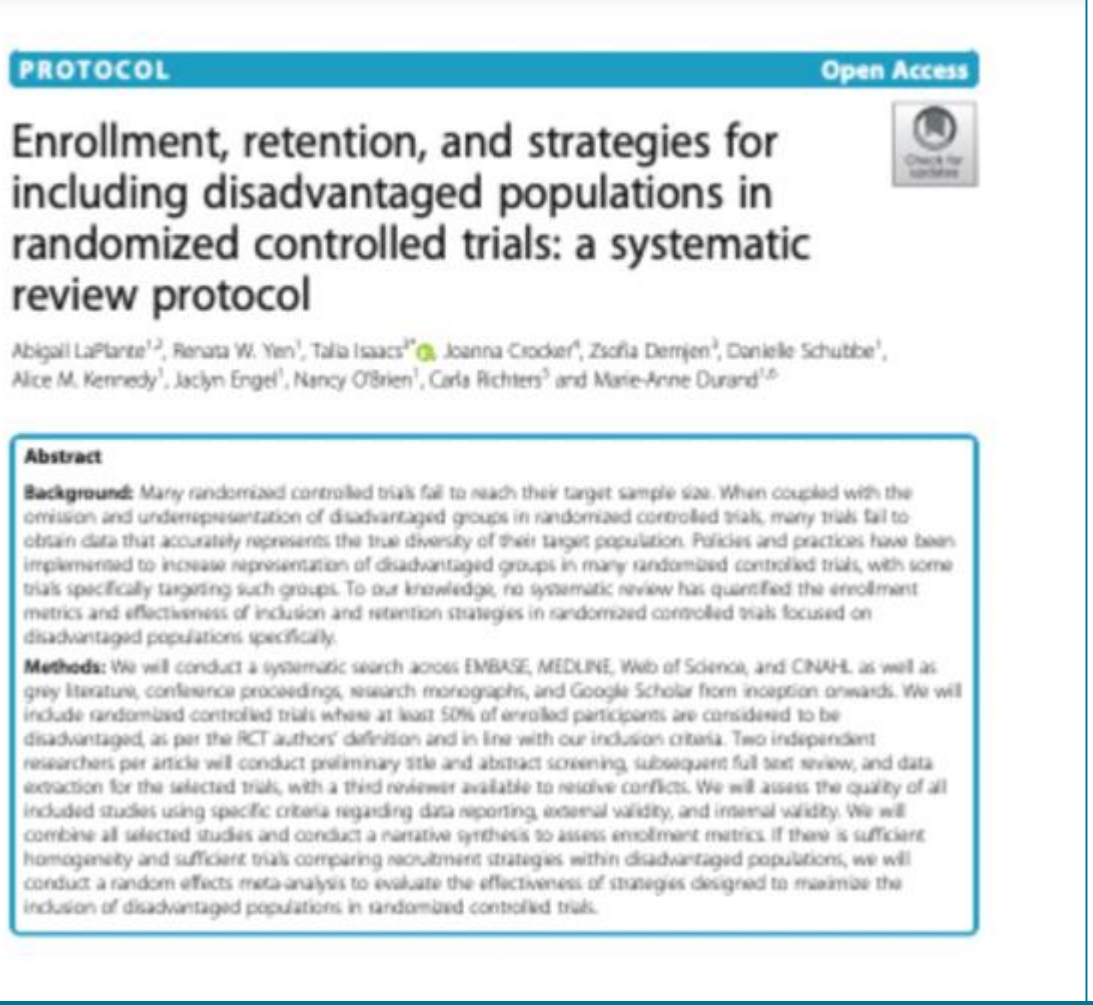
Vous recevrez le résultat chez vous **15 jours plus tard.**

TEST POSITIF

Si le test est positif (sang dans le caca), **allez-voir votre docteur et discutez avec lui/elle** de ce qu'il convient de faire.

Participatory approaches are useful and have become an essential part of conducting SDM and health literacy research with socially disadvantaged populations.

WHAT CAN WE DO BETTER?



PROTOCOL Open Access

Enrollment, retention, and strategies for including disadvantaged populations in randomized controlled trials: a systematic review protocol

Abigail LaPlante[1,2], Renata W. Yeh[1], Talia Isaacs[3*], Joanna Crocker[4], Zsofia Demjen[3], Danielle Schultbe[1], Alice M. Kennedy[1], Jaclyn Engel[1], Nancy O'Brien[1], Carla Richters[5] and Marie-Anne Durand[1,6]

Abstract

Background: Many randomized controlled trials fail to reach their target sample size. When coupled with the omission and underrepresentation of disadvantaged groups in randomized controlled trials, many trials fail to obtain data that accurately represents the true diversity of their target population. Policies and practices have been implemented to increase representation of disadvantaged groups in many randomized controlled trials, with some trials specifically targeting such groups. To our knowledge, no systematic review has quantified the enrollment metrics and effectiveness of inclusion and retention strategies in randomized controlled trials focused on disadvantaged populations specifically.

Methods: We will conduct a systematic search across EMBASE, MEDLINE, Web of Science, and CINAHL as well as grey literature, conference proceedings, research monographs, and Google Scholar from inception onwards. We will include randomized controlled trials where at least 50% of enrolled participants are considered to be disadvantaged, as per the RCT authors' definition and in line with our inclusion criteria. Two independent researchers per article will conduct preliminary title and abstract screening, subsequent full text review, and data extraction for the selected trials, with a third reviewer available to resolve conflicts. We will assess the quality of all included studies using specific criteria regarding data reporting, external validity, and internal validity. We will combine all selected studies and conduct a narrative synthesis to assess enrollment metrics. If there is sufficient homogeneity and sufficient trials comparing recruitment strategies within disadvantaged populations, we will conduct a random effects meta-analysis to evaluate the effectiveness of strategies designed to maximize the inclusion of disadvantaged populations in randomized controlled trials.

Including socially disadvantaged populations in shared decision making and health literacy research remains a challenge.

Do I have to take part?

No, it is your choice. This will not change your work or medical care. You can also stop at any time. If you stop, we will use the information you gave us.

Are there benefits?

You may enjoy doing the surveys, getting information about the COVID-19 vaccines and sharing your opinion. This may help other workers like you in the future.

Comment protégerez-vous ma vie privée ?

Participer à cette étude est confidentiel.

Cela veut dire que les informations que vous partagez ne seront utilisées que par les chercheurs et chercheuses de l'étude.

Les informations que vous partagerez avec les chercheurs et chercheuses seront analysées de façon anonyme. Cela veut dire que votre nom n'apparaîtra pas.

Vous pouvez donc vous exprimer très librement.

Participer à cette étude ne change en rien les soins que vous recevez habituellement chez votre médecin.

Qui puis-je contacter ?

Si vous avez des questions ou si vous voulez plus d'informations :

Marie-Anne Durand **Investigatrice principale**
marie-anne.durand@dartmouth.edu

Aurore Lamouroux **Coordinatrice**
aurore.lamouroux@gmail.com

Niamh Redmond **Cheffe de projet**
niamh.redmond@outlook.fr

Cette étude est financée par l'Institut National du Cancer (INCa)

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DECODE
Littératie en santé

DÉpistage du cancer COlorectal en zones DéfavoriséEs et Littératie en Santé

Brochure d'information

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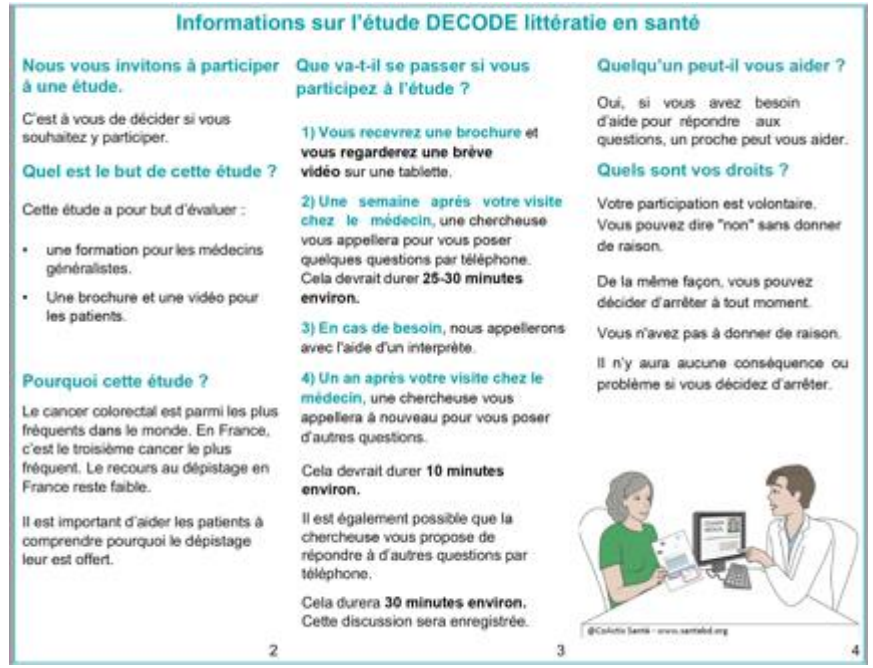


Informations sur l'étude DECODE littératie en santé

Nous vous invitons à participer à une étude.

C'est à vous de décider si vous souhaitez y participer.

Quel est le but de cette étude ?

Cette étude a pour but d'évaluer :

- une formation pour les médecins généralistes.
- Une brochure et une vidéo pour les patients.

Pourquoi cette étude ?

Le cancer colorectal est parmi les plus fréquents dans le monde. En France, c'est le troisième cancer le plus fréquent. Le recours au dépistage en France reste faible.

Il est important d'aider les patients à comprendre pourquoi le dépistage leur est offert.

Que va-t-il se passer si vous participez à l'étude ?

1) Vous recevrez une brochure et **vous regarderez une brève vidéo** sur une tablette.

2) Une semaine après votre visite chez le médecin, une chercheuse vous appellera pour vous poser quelques questions par téléphone. Cela devrait durer **25-30 minutes environ.**

3) En cas de besoin, nous appellerons avec l'aide d'un interprète.

4) Un an après votre visite chez le médecin, une chercheuse vous appellera à nouveau pour vous poser d'autres questions.

Cela devrait durer **10 minutes environ.**

Il est également possible que la chercheuse vous propose de répondre à d'autres questions par téléphone.

Cela durera **30 minutes environ.** Cette discussion sera enregistrée.

Quelqu'un peut-il vous aider ?

Oui, si vous avez besoin d'aide pour répondre aux questions, un proche peut vous aider.

Quels sont vos droits ?

Votre participation est volontaire. Vous pouvez dire "non" sans donner de raison.

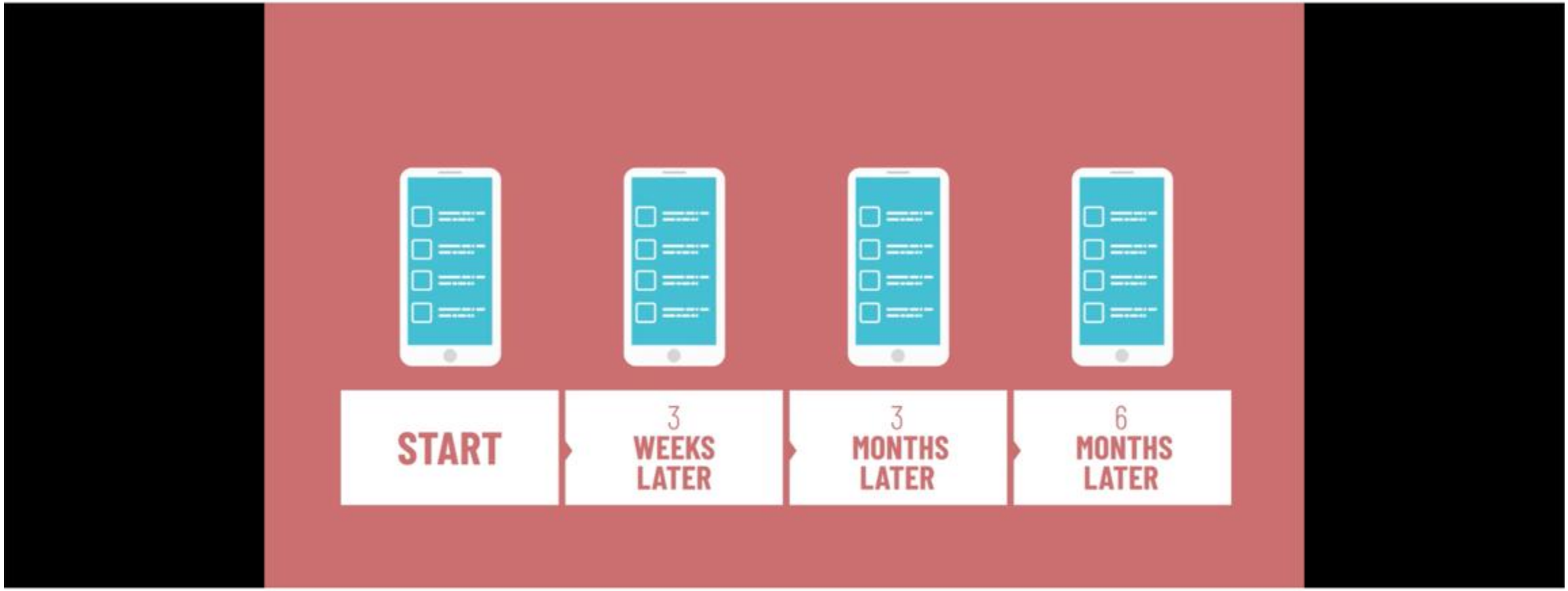
De la même façon, vous pouvez décider d'arrêter à tout moment.

Vous n'avez pas à donner de raison.

Il n'y aura aucune conséquence ou problème si vous décidez d'arrêter.

2 3 4

vimeo Why Vimeo? Features Resources Watch Pricing Search videos, people, and more Log in Join New video



Information Sheet

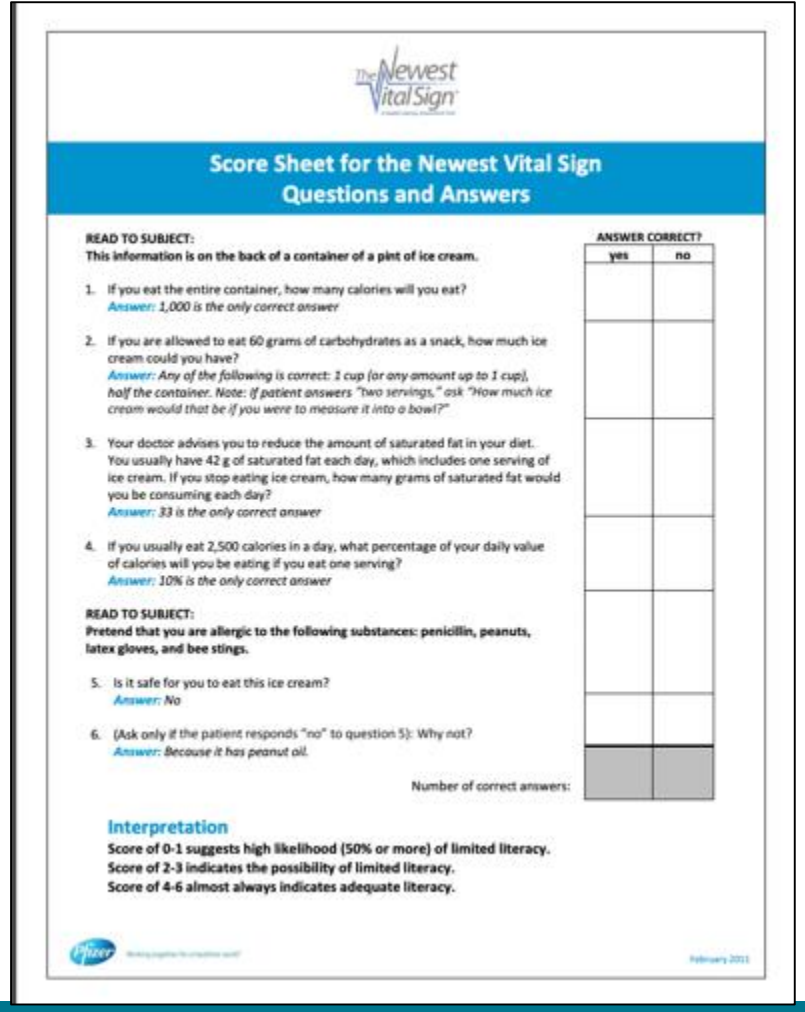
5 days ago | More

Nutrition Facts

Serving Size	½ cup
Servings per container	4
Amount per serving	
Calories 250	Fat Cal 120
	%DV
Total Fat 13g	20%
Sat Fat 9g	40%
Cholesterol 28mg	12%
Sodium 55mg	2%
Total Carbohydrate 30g	12%
Dietary Fiber 2g	
Sugars 23g	
Protein 4g	8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.



The Newest Vital Sign

Score Sheet for the Newest Vital Sign Questions and Answers

READ TO SUBJECT:
This information is on the back of a container of a pint of ice cream.

ANSWER CORRECT?

	yes	no
1. If you eat the entire container, how many calories will you eat? *Answer: 1,000 is the only correct answer*		
2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have? *Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), half the container. Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl?"*		
3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day? *Answer: 33 is the only correct answer*		
4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving? *Answer: 10% is the only correct answer*		

READ TO SUBJECT:
Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream? *Answer: No*		
6. (Ask only if the patient responds "no" to question 5): Why not? *Answer: Because it has peanut oil.*		
Number of correct answers:		

Interpretation

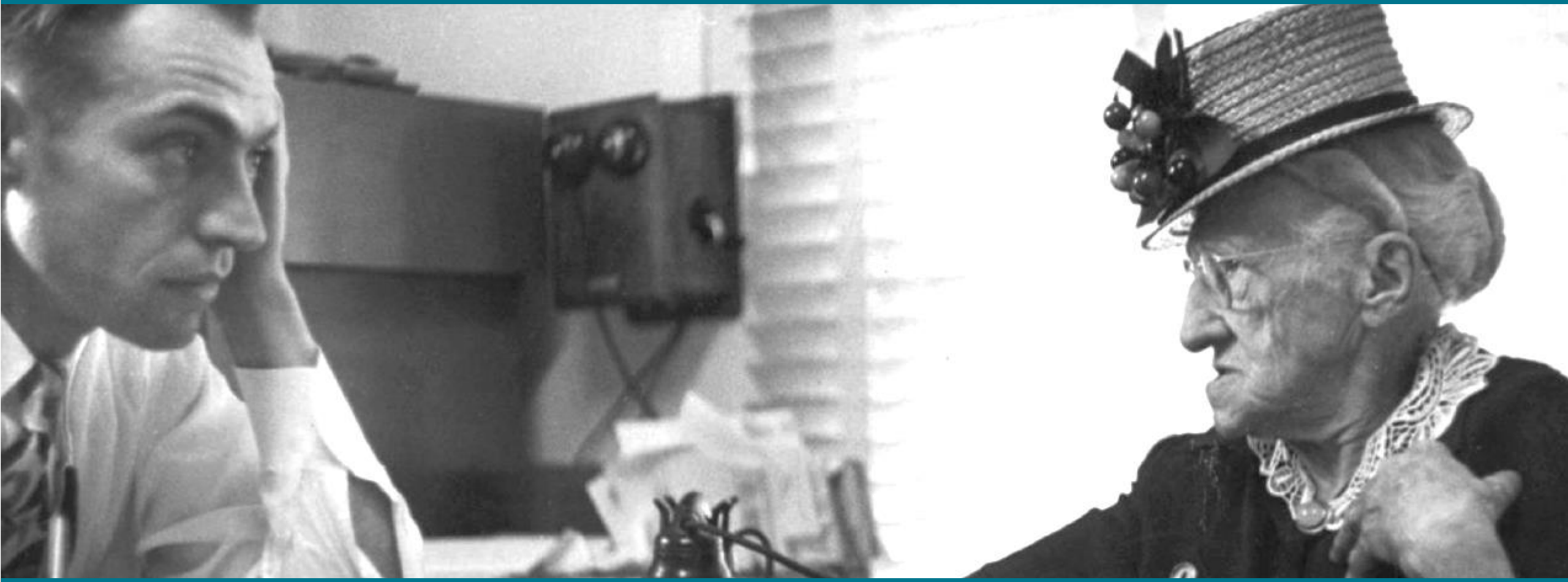
Score of 0-1 suggests high likelihood (50% or more) of limited literacy.
Score of 2-3 indicates the possibility of limited literacy.
Score of 4-6 almost always indicates adequate literacy.

Pfizer

February 2011

Measuring health literacy in underserved populations continues to be difficult.

Thank you



Questions?

marie-anne.durand@inserm.fr/marie-anne.durand@dartmouth.edu