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International experience: Lessons to be learned in regards to informed decisions

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In memory of Joan Austoker

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Objectives for today's presentation are to review:

- ④ Why the working group was formed (2002)
- ④ Products of the working group
- ④ What we have learned

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Why the working group was formed

- ④ Early information campaigns for screening programs focused on encouraging people to participate.
- ④ There was and still is an increased interest in informed choice.
- ④ The scientific and media debate about the harms and benefits of screening stimulated a shift in educational efforts.

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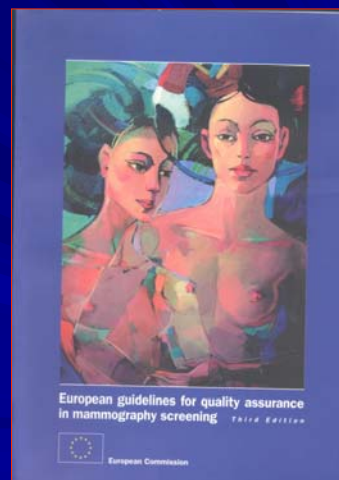
Why the working group was formed

- This led to a shift in mammography program efforts from simply promoting screening to developing messages and decision aids that more fully inform women of the benefits and harms of mammography screening.

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Why the working group was formed

- The third edition (2001) of the European guidelines included a brief chapter on communication.
- This left many unanswered questions.



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Goals of the working group

- ☉ To summarize existing information and decision tools used by individual countries
- ☉ To identify and share best practices

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Products of the working group

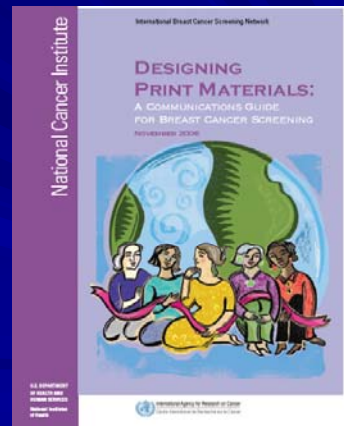
- ☉ Geller BM, Zapka J, Hofvind SS, et al. Communicating with women about mammography. *J Cancer Educ* 2007;22(1):25-31.
- ☉ Zapka JG, Geller BM, Bulliard JL, et al. Print information to inform decisions about mammography screening participation in 16 countries with population-based programs. *Patient Educ Couns* 2006 Oct;63(1-2):126-37

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Products of the working group

- © Designing Print Materials: A Communications Guide for Breast Cancer Screening (2007)

- © <http://appliedresearch.cancer.gov/icsn/publications/guide.html>



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Communicating with women about mammography

- © Reviewed evidence from the literature of currently recommended practices.
- © Surveyed member countries about:
 - Types of communication tools used
 - Content areas included
- © 17/23 countries participated (74%)

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Communicating with women about mammography

Results

- Wide range of communication tools
 - 12 countries had web sites
 - Most used newspaper, TV/radio, posters
- Pamphlet and invitation letter common to all
 - Mailed together in 10 countries
- 7 countries have materials in other languages
 - UK has audiotapes for the blind and special materials for women with learning disabilities

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Communicating with women about mammography

Results (content areas)

- 90% of pamphlets had the following content areas:
 - Description of mammography
 - Recommended intervals
 - Early detection can save lives

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Communicating with women about mammography

📍 Results (content areas)

- Majority of countries also included:
 - Age to start and stop
 - Breast cancer incidence
 - Lifetime risk of breast cancer
 - Earlier detection can reduce treatment
 - False positives
 - Radiation risk
 - Proportion of screened women recalled

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Communicating with women about mammography

📍 Conclusions

- Because misperceptions of the purpose and accuracy of mammography is widespread we need to provide more and balanced information.
- Most countries only included part of what is needed to make an informed decision.

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Print information to inform decisions about mammography screening participation in 16 countries with population-based programs

- Ⓢ **Methods: Literature review of content domains**
- Ⓢ **Medline search (1966-2004); keywords**
 - Mammography, informed decision making, risk communication

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Print information to inform decisions...

- Ⓢ **Methods: *Content analysis* of materials are reported by the following information domains:**
 - General program and mammography information
 - Cancer risk information
 - Test characteristics
 - Benefits of mammography
 - Risks of mammography

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Print information to inform decisions...

Methods

- We reviewed 27 brochures and 9 invitation letters (all translated into English) from 16 countries.
- Audited whether explicit terminology of “decision making” and “pros and cons” were used.
- Documented visuals (drawing, photos) by age, faces, racial diversity.
- Noted font size and rated readability/clutter.

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Print information to inform decisions...

Results

- All materials had some identification data.
- The most common elements were about the general program and mammography information.

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Print information to inform decisions...

☉ The most common elements for cancer risk were:

- Incidence (12/16)
- Risk (10/16)

☉ The most common elements for test characteristics were:

- False positive (15/16)
- False negative (13/16)
- Recall (12/16)

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Print information to inform decisions...

	Benefits of screening					Risks of screening			
	Early Dx	Early Tx	Breast conservation	Find early tumors	Peace of mind	Additional test complications	Radiation	Pain/discomfort	Find unimportant tumors
Australia	X		X	X			X	X	X
Canada	X		X	X	X		X		
Denmark	X		X	X	X	X	X	X	X
Finland	X	X		X			X	X	
France					X			X	
Iceland	X			X			X	X	
Israel	X			X			X		
Italy (Piedmont)	X	X	X	X			X	X	X
Japan	X		X	X			X	X	
Luxembourg	X	X	X	X	X		X	X	
Netherlands	X		X	X			X	X	X
New Zealand	X		X	X			X	X	X
Norway	X		X	X			X	X	
Spain	X								
Switzerland	X		X	X	X	X	X	X	
United Kingdom	X		X	X			X	X	
Total	15	3	11	14	5	2	14	13	5

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Print information to inform decisions...

- ☉ Provides many quotes from the materials.
- ☉ Programs that started earlier included more information about breast cancer.
- ☉ Materials favored persuasion rather than balance.
- ☉ Programs are challenged by the goal of increasing participation while maintaining individual autonomy and choice.

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Designing Print Materials: A Communications Guide for Breast Cancer Screening

- ☉ A small writing group reviewed the literature and wrote this manual published by NCI in 2007.
- ☉ Although written for print material it can be adapted for other media.
- ☉ It is available for free in print or downloadable in black and white or color from the ICSN web site.

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Designing Print Materials

☉ Chapters

- Introduction
- Make a plan
- Assess the needs of your audience
- Develop and test messages and materials
- Maintain your materials
- Epilogue: Looking towards the future

☉ Lots of examples from all over the world

☉ Worksheets in appendices

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Introduction

- ☉ Purpose and organization of guide,
- ☉ Informed Decision Making (IDM) and development of education material
- ☉ Ethical considerations

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Figure I.1 Print Materials Development Cycle



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1. Make a plan

KEY STEPS IN PLANNING

- Identify your purpose for developing written materials
- Specify your communications objectives
- Assess available resources
- Identify potential partners and determine their roles
- Establish a materials development team
- Review existing materials

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2. Assess the needs of your audience

KEY STEPS IN ASSESSING THE NEEDS OF YOUR AUDIENCE

- Identify your overall audience for your brochures and letters
- Recognize the distinguishing characteristics of your audience
- Recognize the relevance of health behavior theory in understanding audiences
- Make preliminary decisions about segmenting your audience
- Learn more about your audiences
- Refine and regroup your audience segments
- Revisit your communications objectives
- Draft a creative brief

3. Develop and test messages and materials

KEY STEPS IN DEVELOPING AND TESTING MESSAGES AND MATERIALS

- Design your messages
- Create a rough draft of your messages
- Refine your messages
- Make preliminary decisions about approach, layout, and visuals
- Pretest your messages and preliminary formats
- Develop your content and visuals
- Pretest your final materials
- Analyze your results and revise your materials
- Make printing and distribution decisions

Make your written materials easy to read and understand

- Ⓢ Write with your audience in mind.
- Ⓢ Make your headers work hard.
- Ⓢ Keep your paragraphs short.
- Ⓢ Consider using a Q & A format.
- Ⓢ Emphasize important points without distracting from readability.
- Ⓢ Write one concept at a time.
- Ⓢ Incorporate IDM concepts

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Make your written materials easy to read and understand

- Ⓢ Frame the information in culturally appropriate ways.
- Ⓢ Define the terms used.
- Ⓢ Use numbers to explain risks and benefits.
 - Use visual aids
 - Present probabilities as natural frequencies using a constant denominator
 - Use as small a denominator as possible

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4. Maintaining your materials

KEY STEPS IN PERFORMING ONGOING QUALITY MONITORING

- Decide whether to update existing materials or develop new materials
- Evaluate your materials

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Epilogue: Looking towards the future

- Applying this knowledge to other cancer screening and other types of health communication

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What we have learned

- ④ IDM is not an easy task
 - Changing perspectives about the role of IDM in people's decisions
 - Balancing public good and individual patient autonomy
 - Cancer and screening tests are complicated:
 - Different risks of cancer depend on multiple factors
 - Different effectiveness of tests due to factors related to the participant, the test operator and the equipment
 - Evolution of evidence about tests

What we have learned

- ④ Cancer screening communications
 - We need to clearly communicate our decisions to the public.
 - Communication is interactive.
 - We are obligated to communicate so that we are understood.
 - The information provided needs to be useful to the person receiving it.

Provide fair and balanced information to lead the way!

Thank you!



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