

Communicating Clinical Practice Guidelines to patients and the public: An analysis of patient versions

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Declaration of interests

- Member of the GRADE Working Group
- Member of the DECIDE Collaboration
- McMaster University

- Funding from

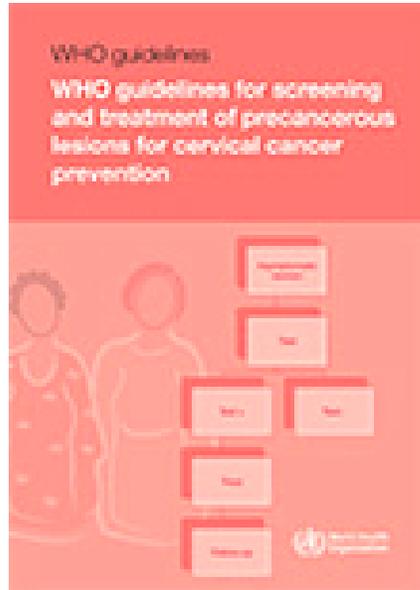


Canadian Institutes of Health
Research Fellowship
Knowledge Translation

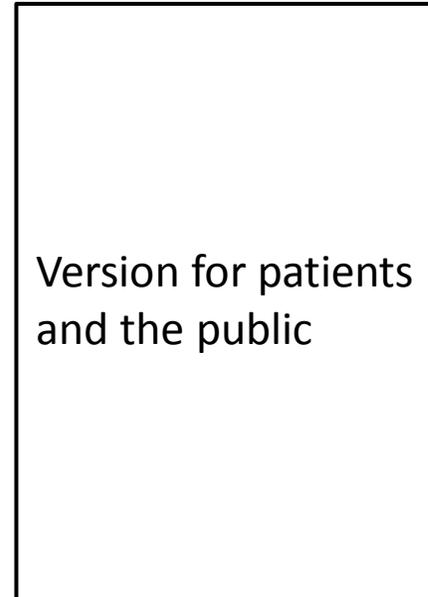
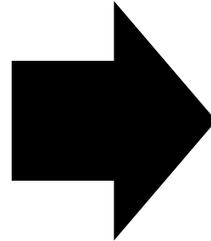


DECIDE project: Strategies to communicate evidence based recommendations

Work Package 3 Patient and Public focus



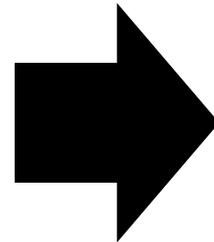
Clinical Practice Guidelines



Version for patients and the public

DECIDE project: Strategies to communicate evidence based recommendations

Work Package 3 Patient and Public focus



Version for patients and the public

Guideline Development Tool: GDT
www.guidelinedevelopment.org

DECIDE project: Strategies to communicate evidence based recommendations

Work Package 3 Patient and Public focus

- What do people think about guidelines? Systematic review
- What do people want from guidelines? Focus groups
- What is currently provided and what can we learn? Content analysis

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- What do people want from guidelines? Focus groups
- **What is currently provided and what can we learn? Content analysis**

The Sample: learn from others

Search for guideline/recommendation producers

- National Clearing House, GIN Library, the Canadian Medical Association Infobase, NHMRC CPG Portal, NICE Evidence Search
- at least 4 patient versions from 2012-2014



American Urological Association



Royal College of Obstetricians and Gynaecologists

Bringing to life the best in women's health care



U.S. Department of Health and Human Services
Centers for Disease Control and Prevention



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NICE National Institute for Health and Care Excellence

The Sample: learn from others

Search for guideline/recommendation producers

- National Clearing House, GIN Library, the Canadian Medical Association Infobase, NHMRC CPG Portal, NICE Evidence Search
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17 guideline producers

Random sample of 2 patient versions = 34

Directed content analysis



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Content analysis

Name
Topic
Length
Format
Location
Credibility
Personalisation
Background information
Health services information
Evidence
Factors in decision making
Recommendation
Purpose(s)

Personalisation of information

Difficult for people to apply the results of research to themselves

- 'I am an individual'
- 'My disease is different'
- 'This does not apply to me'



Personalisation of information

Inspired to Pay It Forward

At age 58, in the midst of my role as Under Secretary of State for Arms Control and International Security, I was diagnosed with stage III esophageal cancer. In 1973 my dear grandmother, Marie O'Kane, my father's mother, was diagnosed with stage III esophageal cancer and the memories of her experience came flooding back. In my vulnerable state I wanted answers to take back control and to empower myself to fight back. I wanted credible information to assist with my decision making, leading to making the best choice regarding my care and the

this diagnosis. This is my way to 'pay it forward', so to speak, and help all cancer patients become cancer survivors.

My survival and high quality of life can be directly traced to my oncology team, Tommy D'Amico, MD, and Scott Balderson, PA-C. Their care, work with NCCN, and dedication to these guidelines are exceptional. I have also been enormously blessed in my life. I have a loving



Ellen O. Tauscher

1/34 used a personal story

Personalisation

I am HIV infected and pregnant. When should I start taking anti-HIV medications?

Very few used brief clinical scenarios

Purpose



PERGAMON

Social Science & Medicine 52 (2001) 1417–1432

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Writing wrongs? An analysis of published discourses about the use of patient information leaflets

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Patient and public attitudes to and awareness of clinical practice guidelines: a systematic review with thematic and narrative syntheses

Kirsty Loudon^{1*†}, Nancy Santesso^{2†}, Margaret Callaghan³, Judith Thornton⁴, Jenny Harbour³, Karen Graham³, Robin Harbour³, Ilkka Kunnamo⁵, Helena Liira³, Emma McFarlane⁴, Karen Ritchie³ and Shaun Treweek⁶

Provide education

- information about the disease, the tests or treatments



- PICOs
 - Systematic reviews
 - Summary of evidence
 - Patient values and preferences
 - Resources
 - Feasibility
 - Acceptability
 - Equity
- RECOMMENDATION**

Provide education

- information about the disease, the tests or treatments

The Task Force Recommendations on Screening for Cervical Cancer: What Do They Mean?

Here are the recommendations. When the Task Force recommends screening, it is because the screening has more possible benefits than possible harms. When the Task

½ distinguished the recommendations by a heading

Provide advice

These treatments are described in the sections that follow.

Other methods of assisted reproduction called gamete intrafallopian transfer (GIFT) or zygote intrafallopian transfer (ZIFT) are not recommended.

Certain forms of assisted reproduction (IUI, IVF, ICSI, donor insemination and egg donation) are regulated by law and their use is controlled by the Human Fertilisation and Embryology Authority (HFEA; www.hfea.gov.uk).

Intrauterine insemination

Intrauterine insemination (IUI) is a type of artificial insemination where sperm is placed at the cervix (the neck of the uterus).

If you are using ICI you have a higher chance of pregnancy (if you have previously been frozen). However, IUI is only used if you have previously frozen then thawed sperm.

You may be offered IUI if:

- you and your partner are unable to have a child naturally, for example because of a physical condition.
- you have a condition (such as a cervical mucus problem) where you need specific help to conceive and conception can take place.
- you are in a same-sex relationship and using donor sperm for insemination.

You should be offered unstimulated IUI or you may be offered to stimulate your [ovaries](#) during treatment. This is called [ovulation induction](#) to give you the best chance of pregnancy.

How will movement problems be treated?

If you have had a moderate or severe brain injury this may affect your balance and movement, leading to problems with walking and other everyday activities.

Research has shown that practising everyday tasks over and over again is helpful. Your healthcare team may encourage you to practise walking, getting from sitting to standing or lifting or moving small objects with your hands and fingers. Practising everyday tasks is more helpful to your recovery than doing general exercises.

If your joints are not in the right position because of tightness in the muscles, it may help to wear a splint or a cast to prevent further tightening and improve the position of your limb. Splints are removable supports made of plastic or metal, while casts go around the whole limb and are normally made of plaster. You may also be given exercises to stretch your muscles.

You may be offered injections of Botulinum neurotoxin (sometimes called Botox, Dysport or Xeomin) to help with tight muscles. It is best for the doctor who is giving the injections to work with your physiotherapist or your occupational therapist (or both) so that together they get the best result from the effect of your injection.

Your doctor may also consider giving you the medicines baclofen and tizanidine to help ease tightness in the muscles following your brain injury.

Other half?

Provide education

IVF is more effective for women who have been pregnant or had a baby before. The chances of having a baby fall with the number of unsuccessful cycles of IVF you have already had.

80% mentioned benefits

60% mentioned harms

Assist with decision making

Information	Percentage
Benefits	80%
Harms	60%
Feasibility/accessibility	50%
Values and preferences	30%
Costs	15%



Help with consultation

Questions to Ask Your Healthcare Professional

When Talking About OAB

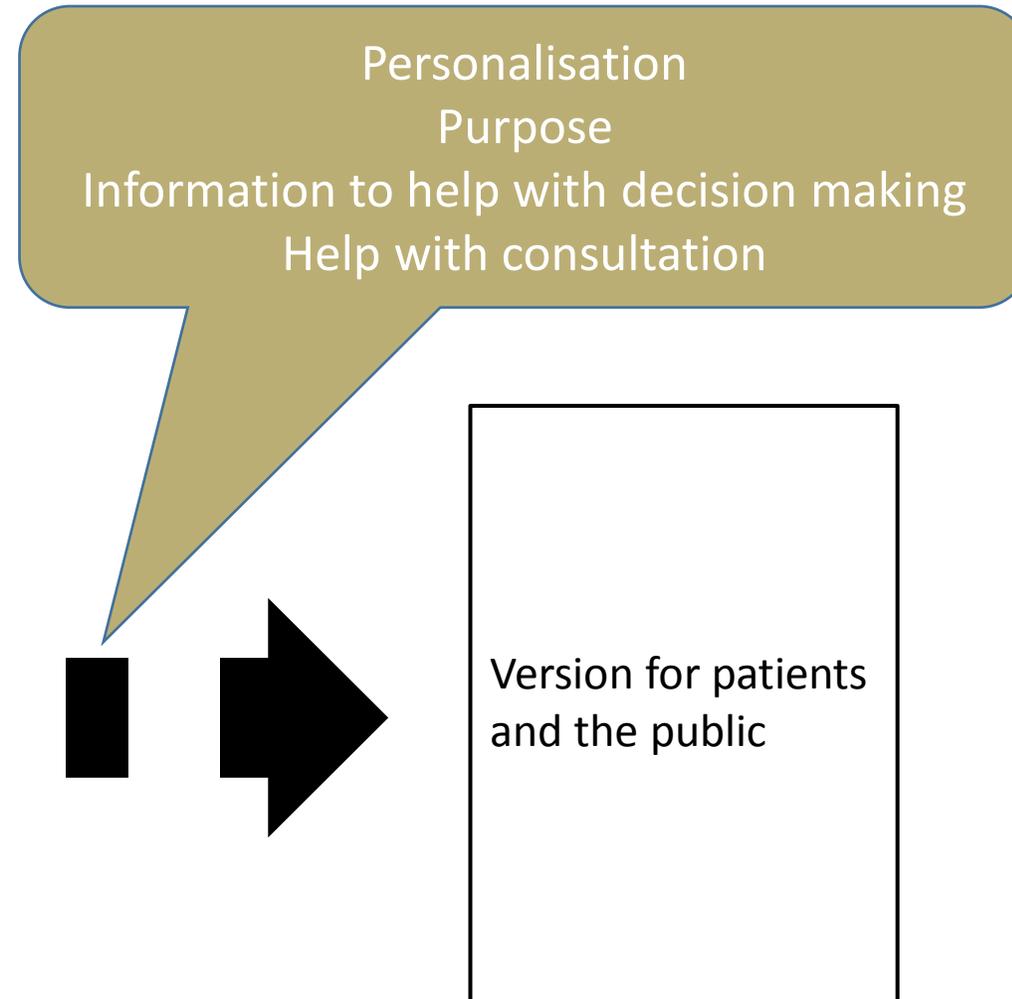
- ▶ What is Overactive Bladder (OAB)?
- ▶ What causes OAB?
- ▶ Can you prevent OAB?
- ▶ Can you cure OAB?
- ▶ Can you help me? Or, do I need to see a specialist? If I need a specialist, how can I find the right one for me?
- ▶ Will I need to have tests to find out if I have OAB?

5/34 included a 'questions to ask your doctor' section

Conclusions



Clinical Practice Guidelines



Conclusions

Examples of strategies to fill those gaps

Research focus:

- Personalisation of information
 - Different purposes
 - Communication of evidence – words versus numbers
 - Wording of recommendations
-
- Additional research needed to test different formats