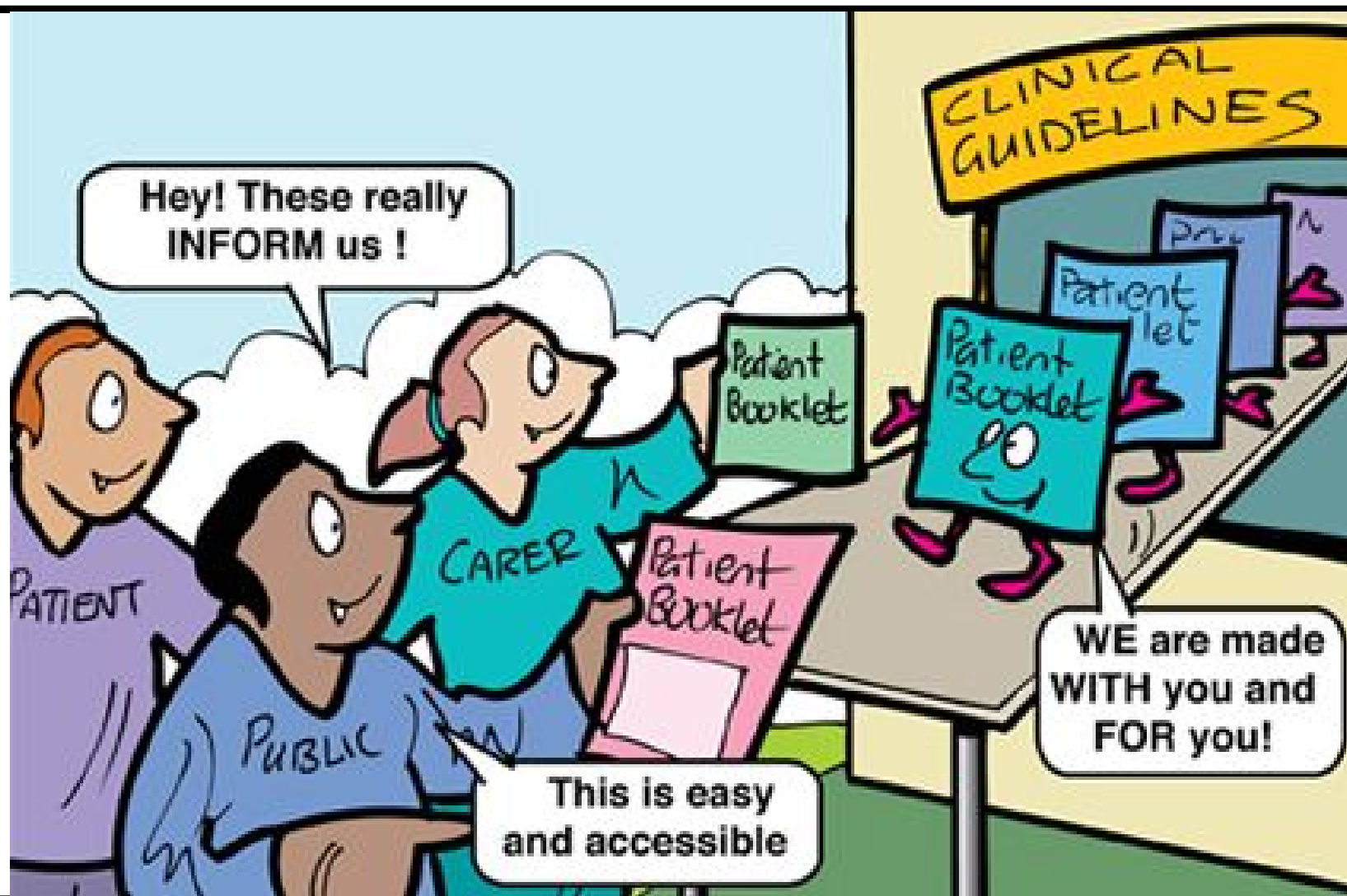


**Public attitudes to  
and knowledge of healthcare guidelines,  
and  
methods to communicate guideline  
recommendations  
to patients and the public.**

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It's a stupid system, a waste of money, and, without rigorous standards of searching and appraisal, much of the information is biased and misleading—especially in terms of fair representations of risk"

Muir Gray told the *BMJ* reflecting on the current situation in the NHS (*July 2013*).

1. To identify and evaluate evidence on the public's attitudes and knowledge of clinical practice guidelines, evidence-based recommendations, or systematic reviews.
2. To identify strategies that have been used to communicate guideline recommendations to the public

- **Search strategy:** We searched health databases from 2000 to January 2013 for any study design, grey literature (including websites of international guideline producers), and we contacted guideline producers.
- **Methods:** Two reviewers independently abstracted, coded, assessed quality, analysed and synthesised themes from the studies.

### Results

- We found 5415 studies and included 28 published studies and two reports (NICE, SIGN) with a total of 22,210 individuals: 10 qualitative studies, 16 cross sectional studies and 4 RCTs.
- Diverse populations: Canadian office workers, female caregivers in Maryland, USA, Londoners attending drop in centres for patients with mental health problems, Seoul visitors to a welfare centre, women attending secondary care for menstrual abnormalities in Leicestershire, and patients with diabetes in Australia.

- Awareness of existence of guidelines
- Knowledge of guideline content
- Attitudes towards guidelines,  
acceptance and perception of guidelines
- Presentation strategies used to communicate  
guideline information

Huge variation in awareness of guidelines

0% to 79%

- **Colorectal cancer guidelines, Australia**  
NONE of 33 people WITH colorectal cancer taking part in interviews aware of them, although all participants would have loved a copy (Mitchell and White)
- **Breast cancer follow-up & self-help guidelines, USA**  
NONE of 39 women in focus groups aware of guidelines, Health professionals had not provided (Royak-Schaler)



- *Dietary Guidelines for Americans*  
*Keenan 2002*

When 400 people in Minnesota were tested on dietary guidelines, out of 13 recommendations, average recall was less than 2.5

- Unfamiliar with and sometimes confused by the terms “medical evidence,” “quality guidelines,” and “quality standards”

Carman 2010

### Subthemes

- **Properties of guidelines:** Format issues; Writing – level of detail; Credibility (need for approval by physician before use); Evidence behind recommendations
- **Applicability of guidelines:** Patient as individual, Applicability of information
- **Use of guidelines for patient:** Communicate with physician; Decision making; Self- management
- **Use of guidelines for health care system and physician:** Guidelines control care (restrict/offer, access, cost); Guidelines as rules; Guidelines for physicians

Positive response – communicate with Doctors  
(NICE)

*The psychiatrist was very reluctant to refer my husband for psychological therapies as he felt he was “pharmaceutically well controlled”. We were able to use NICE guidelines to argue his case for **talking therapies** which have really helped him*

Negative response from Doctor (NICE)

*It was not my position to offer advice to them...*

*I feel in a bit of a state of conflict about NICE . . . somebody needs to take responsibility [for rationing] . . . but where they make a decision about, “well this drug only helps a very tiny percentage of people . . . and therefore should we be funding it?” . . . It almost pulls into question the value of individuals’ lives, and who has a right to place a value on that?”*

- Product & formatting the guideline
- How to get the product out there

Berry 2008

*I think probably some recommendations at the front. I mean that's usually what I'm looking for, especially if it's for preventive, if you can have those on the first page or very close to it."*

Didn't like **format**. Want **personal stories**, interesting so want to read it, didn't like **inappropriate cartoons**, liked internet-based media and suggest celebrities success stories

Berry 2008

*To me, Pierre is a character. And I don't necessarily think Pierre fits. . . . This is like, researchers [saying] yeah, 'Oh, good. Pierre is 55' but, Pierre means nothing except for a cartoon to me."*



- Berry 2008

“God help me  
for saying this but,  
Oprah, fantastic!  
You see her talk about  
her own struggle  
or to read someone’s  
blog.  
It’s their own personal  
story.”

### Implications for guideline developers:

- Increase awareness of clinical guidelines
- Develop patient guidelines that are personally applicable, trustworthy and useful for patients and carers managing their care

- Thank you to my fellow authors in particular :  
My co-author Nancy Santesso



- Margaret Callaghan



Jenny Harbour , Karen Graham, Robin Harbour, Karen Ritchie

- Also Judith Thornton  
And Emma McFarlane



- Ilkka Kunnamo and Helena Liira



- Shaun Treweek



Thank you for your attention!

FURTHER INFORMATION

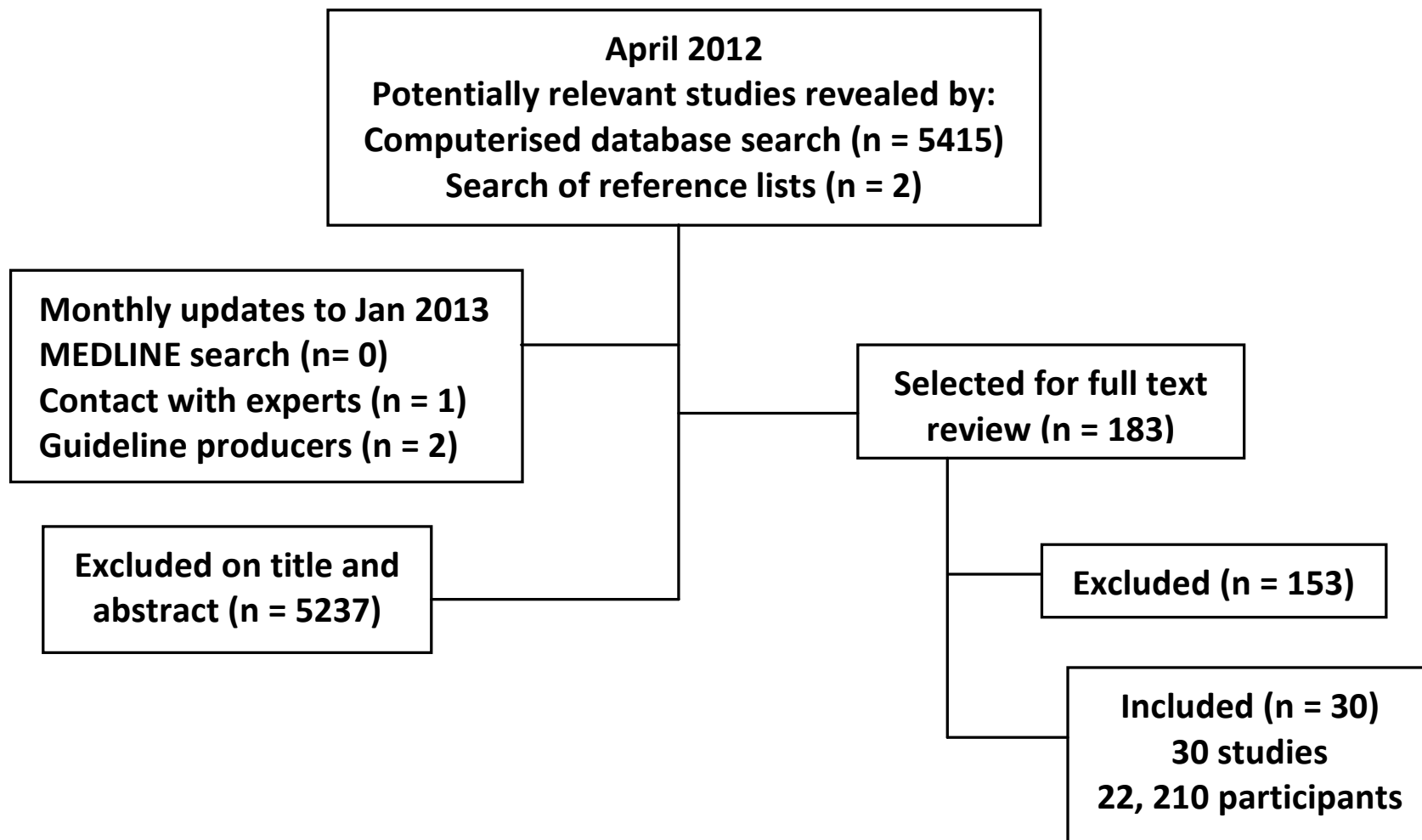
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Study	Quality assessment
Berry 2010; Crocetti 2004; Elad 2011; Julian 2010; Matti 2010; Moffett 2005; Quintana 2010; Squiers 2011	Good
Carman 2010; Cameron 2007; Copeland 2005; Keenan 2002; Miroballi 2012; Mitchell and White 2004; NICE 2012; Owen-Smith 2010; Roth 2010; Royak-Schaler 2008; SIGN 2011; Singer 2004; Spence 2002	Fair
Dykes 2004; Faruqi 2000; Geiger 2001; Hong 2007; Nash 2003	Poor
Akl 2007; Michie 2005; Ostwald 2001; Reich 2010	Unclear

Author/ Year	Aim	Participants and study location	Key findings reported by authors	Key themes identified by reviewers*
Berry 2010	To gain an understanding of public perceptions of Physical Activity guidelines put forward by a public health agency	22 participants, 5 focus groups, 18-70 yrs old, exercised < 3 times a week & people with Type II diabetes or cardiovascular disease. Canada	Didn't like <b>format</b> . Want <b>personal stories</b> , interesting so want to read it, didn't like <b>inappropriate cartoons</b> , liked internet-based media and suggest celebrities success stories	<b>Patient as individual</b>  <b>Applicability of guidelines</b>  <b>Format</b>





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