

# Stakeholder engagement in the scoping phase of clinical guideline development: Challenges and solutions

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# The referral and scope

- Each topic for clinical guideline development is referred to NICE by the Department of Health, based on recommendations from topic selection consideration panels.
- The referral is then translated into the Scope which provides a framework within which to develop the guideline. The scope describes:
  - the epidemiology of the disease/condition,
  - the key clinical issues;
  - the population and aspects of care that the guideline will and won't cover.

# Stakeholders and scoping the CG

- Stakeholder organisations can be:
  - Commercial
  - Health care provider
  - Patient/Carer
  - Professional
  - Research
  - Social Care
  - Statutory
- The scope is developed after consultation with stakeholders at two key stages:
  - A pre-consultation stakeholder workshop;
  - A 4 week consultation period.



# Aims

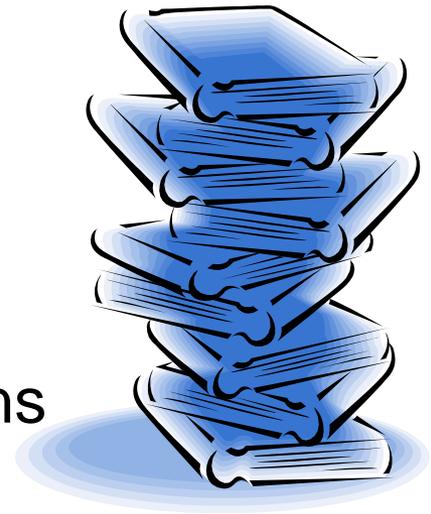
1. To review stakeholder involvement during the scoping phase of clinical guidelines that commenced since January 2009;
2. To identify opportunities for further facilitating active stakeholder engagement during guideline development.

# Approach:

1. To undertake an audit of stakeholder involvement in all clinical guidelines that commenced the scoping process during 2009.
2. To seek the views of stakeholders who attended the pre-consultation scoping workshops; and
3. To examine stakeholder comments submitted during consultation through a thematic analysis.

# 1. Audit of stakeholder involvement

- Dataset comprises:
  - 18 Clinical Guidelines
    - 5 Short Clinical Guidelines (SCG's)
    - 2 NCC-Cancer
    - 4 NCC-Mental Health
    - 5 NCGC-Acute and Chronic Conditions
    - 2 NCC-Women and Children's Health



# Number of Stakeholders

- Across 18 guidelines there were an average of 110 (range 55 to 186) registered stakeholders/guideline topic;
- Number of SH's appears topic (breadth) dependent
  - Topics with most SH's:
    - “Recognition, referral and diagnosis of ASD” (n=187);
    - “Assessment and management of psychosis with substance misuse” (n=178)
  - Topics with fewest SH's:
    - “Ablative therapy for treatment of Barrett's oesophagus” (n=56);
    - “NIV in the management of motor neurone disease” (n=61)
- There were an average of 24 stakeholders/guideline (range: 6 [Barrett's Oesophagus] - 47 [stroke rehabilitation]) attending each scoping workshop.

# Who are our stakeholders?

SH 'type'	Registered (%)	Workshop (%)
Commercial	11.9	19.3
Health Care Provider	34.6	27.6
Patient/Carer	8.8	11.8
Professional	22.2	33.8
Research	3.6	4.1
Social Care	3.7	9.1
Statutory	17.6	8.4

## 2. Views of workshop attendees

Data set:

- Between January and February 2010, attendees at 6 scoping workshops were asked to complete questionnaires that sought to assess views on the workshop and the broader scoping process.
- Average response rate: 38.2% (range 25.0-62.5%)

# Views of workshop attendees-(1)

- Communications:
  - There was general agreement that the existing methods of communicating information on the date/timing of the scoping workshops was adequate;
  - Around half (49%) of attendees were contacted directly by NICE and invited as registered stakeholders;
  - A further 43% had the invitation forwarded to them by registered stakeholders;
  - Around 4% of respondents initiated contact with NICE.

# Views of workshop attendees-(2)

- Attendees:
  - Respondents were split over whether the 'right people' were in attendance at the workshop.
  - Around 41% felt the makeup of the attendees was correct, however, 14% replied that the make-up was 'wrong' and a further 22% had expected certain groups to be better represented.
  - Responses suggest that attendees at two workshops (UGI bleeding and Spasticity in Children) were particularly concerned about whether the 'right people' were in attendance.

# 3. Scope consultation

- Audit data:
  - On average, 17% of registered stakeholders and 36% of workshop attendees submit written comments during consultation;
  - On average, 32.4% (range: 12.4-51.1%) of registered stakeholders either attend the workshop OR submit written comments.
  
- Thematic analysis:
  - Consultation comments from 5 guidelines (February 2009-April 2010) were assessed;
  - A total of 453 comments were received and 12 themes emerged from the collected comments.

Themes	1	2	3	4	5	Total
Terminology	3	-	1	10	-	<b>14</b>
Inclusions	15	15	16	19	20	<b>85</b>
Exclusions	1	-	1	1	4	<b>7</b>
Comparators	8	-	-	2	-	<b>10</b>
Outcomes						
- Clinical	1	-	1	5	2	<b>9</b>
- Cost	-	-	-	-	-	<b>-</b>
Supportive of approach	11	20	24	10	18	<b>83</b>
DH remit	-	-	-	2	-	<b>2</b>
Information	9	21	22	39	12	<b>103</b>
Corrections & Clarifications	20	17	35	35	32	<b>139</b>
Implementation issues	1	-	-	-	-	<b>1</b>
<b>Totals</b>	<b>69</b>	<b>73</b>	<b>100</b>	<b>123</b>	<b>88</b>	<b>453</b>

# The challenges:

- How to identify all 'relevant' stakeholder organisations for each clinical guideline?
- How to engage/encourage stakeholder organisations to register an interest in the guideline?
- How to ensure all stakeholders are given an equal opportunity to engage in the consultation process (i.e. attend the workshop and/or respond to the consultation process)?
- How to assess/monitor?

# The 'solutions'?

- To be more proactive in identifying and recruiting stakeholder organisations at the scoping stage?
  - Resourcing implications.
- To identify facilitators/barriers to active engagement in the consultation process.
- Others?