

## Patient participation in Delphi surveys to develop core outcome sets: systematic review

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### Supplementary tables

**Table 1a – Study characteristics (professional participants)**

| Professional recruitment source & approach <sup>a</sup>            |                       |
|--|-----------------------|
| Professional recruitment source                                    | n (%)                 |
| Professional organisation  | 49 (70%)              |
| Publication authors (including Cochrane authors)                   | 22 (31%)              |
| Research study   | 13(19%)               |
| Research group / consortium /CTU groups (including Cochrane group) | 32 (46%)              |
| Steering group members / contacts / University contacts            | 14 (20%)              |
| Treatment centres  | 15 (21%)              |
| Snowball sampling  | 25 (36%)              |
| Other <sup>b</sup>   | See below             |
| Not reported   | 8                     |
| Professional recruitment approach                                  | n (%)                 |
| Email invitation   | 50 (91%)              |
| Postal invitation  | 4 (7%)                |
| Handed invitation  | 4 (7%)                |
| Newsletter / webpage   | 5 (9%)                |
| Unclear  | 3                     |
| Not reported   | 20                    |
| Participant characteristics reported                               |                       |
| Professional participants  | n (%)                 |
| Clinical experience  | 20 (26%)              |
| Research experience  | 9 (12%) <sup>c</sup>  |
| Gender   | 24 (31%) <sup>d</sup> |
| Age  | 21 (27%) <sup>e</sup> |
| Ethnicity  | 4 (5%) <sup>c</sup>   |
| Education  | 3 (4%) <sup>f</sup>   |

#### Footnotes

<sup>a</sup> More than one recruitment source could be used

<sup>b</sup> Other included journal editorial groups (9), through informal mailing lists (n=2), members of steering committee (n=2), conference / conference special interest group (n=4) email discussion group / special interest group (n=4), research funding organisation (n = 2), audit participant (n=1)

<sup>c</sup> Includes 2 studies where characteristic reported collectively on research experience and ethnicity for PE and LE

<sup>d</sup>Includes 9 studies where characteristic reported collectively on gender for professionals and patients

<sup>e</sup>Includes 5 studies where characteristic reported collectively for professionals and patients

<sup>f</sup>Includes 1 study where characteristic reported collectively for professionals and patients

**Table 1b - Study development and design characteristics of the Delphi studies**

| Study design & development characteristics   |                                     |
|--|-------------------------------------|
| Number of rounds where patients participated | n (%)                               |
| 1  | 13 (17%)                            |
| 2  | 28 (36%)                            |
| 3  | 37 (47%)                            |
| Number of stakeholder participant categories | n (%)                               |
| 2  | 31 (40%)                            |
| 3  | 20 (26%)                            |
| 4  | 16 (21%)                            |
| 5  | 10 (13%)                            |
| 6  | 1 (1%)                              |
| Number of reported items per round           | Descriptive statistics <sup>a</sup> |
| Round 1 (n=71)                               | Median = 46, Min = 9, Max = 130     |
| Round 2 (n=53)                               | Median = 49, Min = 8, Max = 130     |
| Round 3 (n=28)                               | Median = 37, Min = 7, Max = 114     |

**Footnote**

<sup>a</sup>excluding not reported, n/a, unclear

**Table 2a – Delphi characteristics rounds 2 and 3**

| Scoring System Rounds 2 & 3                                |                     |                  |
|--|---------------------|------------------|
| Scoring system   | Round 2<br>n (%)    | Round 3<br>n (%) |
| 1-9 / 1-10 <sup>a</sup>                                    | 52 (85%)            | 26 (77%)         |
| 0-4/1-4 / 1-5  | 4 (7%)              | 3 (9%)           |
| 9/10/12 most important outcomes                            | 2 (3%) <sup>b</sup> | 1 (3%)           |
| Yes/no/don't know or agree/disagree/unsure                 | 2 (3%)              | 1 (3%)           |
| Yes/no/include in COS & Essential and recommended outcomes | n/a                 | 3 (9%)           |
| Domain inner core, middle ring, outer ring                 | 1 (2%)              | n/a              |
| Not reported   | 2                   | 1                |
| Unclear  | 2                   | 2                |
| n/a patients only in 1 round                               | 13                  | 13               |
| n/a only 2 rounds  | 0                   | 28               |
| Feedback   |                     |                  |
| Feedback type Round 3                                      | n (%)               |                  |
| All stakeholder groups combined                            | 7 (28%)             |                  |

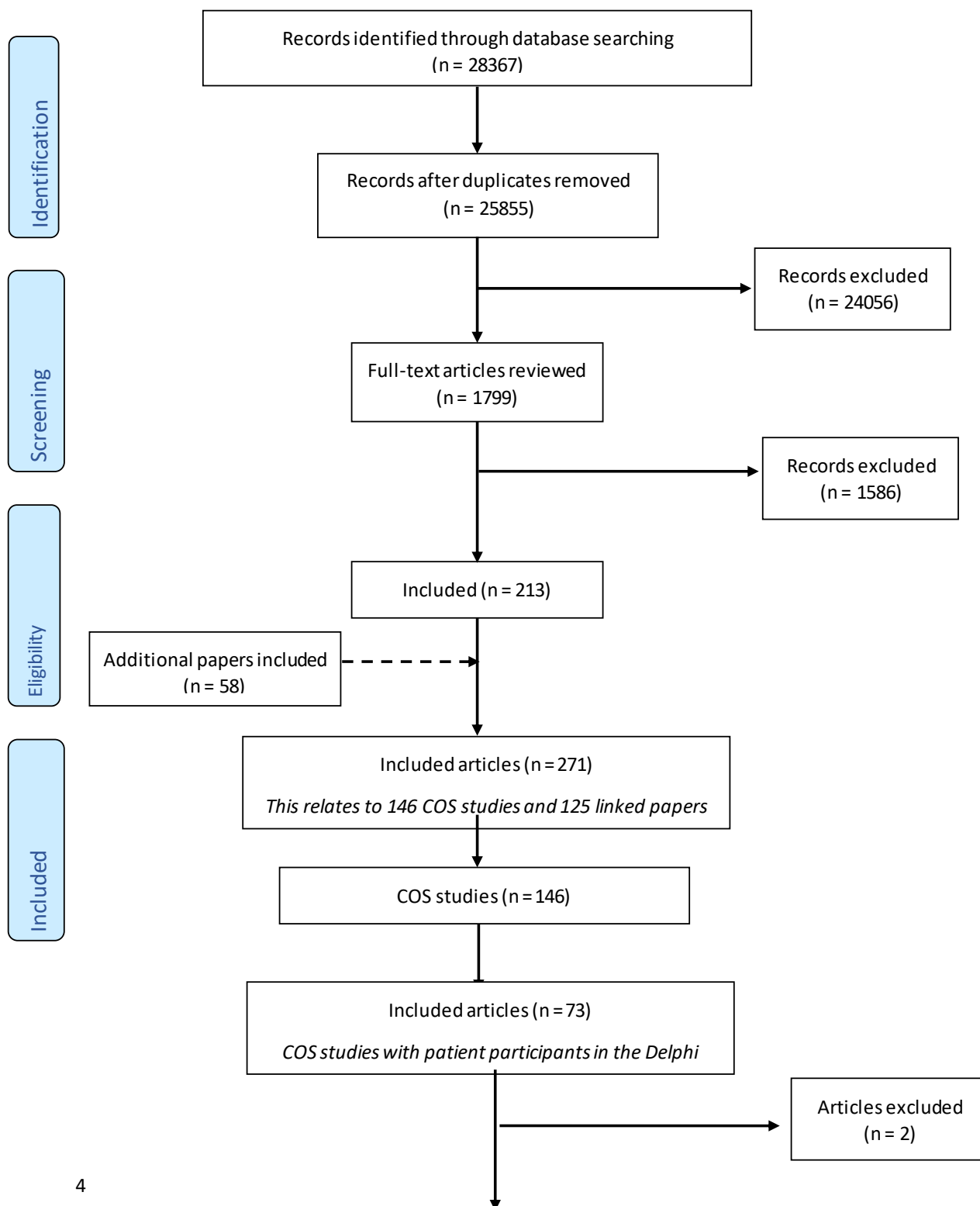
|  |         |
|--|---------|
| Stakeholder groups reported separately                   | 9 (36%) |
| Own stakeholder group                                    | 1 (4%)  |
| Each stakeholder group & all stakeholder groups combined | 3 (12%) |
| Own stakeholder group & all stakeholder groups combined  | 3 (12%) |
| SWAT   | 2 (8%)  |
| Not reported   | 6       |
| N/a only 2 rounds  | 28      |
| N/a patients only took part in one round                 | 13      |
| Unclear  | 6       |

**Footnotes**

<sup>a</sup>Only two studies used 1-10

<sup>b</sup>Caregivers scored differently to patients in one of these studies – patients used score cards

**Supplementary Figure 1** - Preferred Reporting Items for Systematic Reviews and Meta-Analyses flowchart of identification of eligible studies from the COMET database. Data were extracted from the COS systematic reviews



Included articles (n = 71)

*COS studies with more than one patient participant in  
the Delphi*