# Supplementary file: Additional tables and figures

**Supplementary table 1: COS in eligible papers**

|  |  |  |  |
| --- | --- | --- | --- |
|  | | **Papers** | **COS** |
| One COS reported over one paper | | 197 | 197 |
| Multiple papers reported the same COS | 24 COS reported in two papers | 48 | 24 |
| 6 COS reported in three papers | 18 | 6 |
| 1 COS reported in four papers | 4 | 1 |
| 1 COS reported in five papers | 5 | 1 |
| 1 COS reported in six papers | 6 | 1 |
| Multiple outcome sets reported in the same paper | Five papers reported two outcome sets | 5 | 10 |
| One paper reported three outcome sets | 1 | 3 |
| Two papers reported four outcome sets | 2 | 8 |
| One paper reported five outcome sets | 1 | 5 |
| One paper reported six outcome sets | 1 | 6 |
| **TOTAL** | | **288** | **262** |

**Supplementary table 2: Health area**

|  |  |  |  |
| --- | --- | --- | --- |
| **Health Area** | **Routine care only (n=164)** | **Routine care and research (n=98)** | **All (n=262)** |
| Heart and circulation | 23 (14%) | 12 (12%) | 35 (13%) |
| Cancer | 22 (13%) | 8 (8%) | 30 (11%) |
| Orthopaedics and trauma | 13 (8%) | 16 (16%) | 29 (11%) |
| Rheumatology | 14 (9%) | 7 (7%) | 21 (8%) |
| Neurology | 11 (7%) | 9 (9%) | 20 (8%) |
| Infectious diseases | 10 (6%) | 2 (2%) | 12 (5%) |
| Lungs and airways | 4 (2%) | 8 (8%) | 12 (5%) |
| Blood disorders | 5 (3%) | 6 (6%) | 11 (4%) |
| Child health | 9 (5%) | 2 (2%) | 11 (4%) |
| Effective practice/health systems | 9 (5%) | 1 (1%) | 10 (4%) |
| Eyes and vision | 4 (2%) | 6 (6%) | 10 (4%) |
| Other | 5 (3%) | 4 (4%) | 9 (3%) |
| Pregnancy | 7 (4%) | 2 (2%) | 9 (3%) |
| Mental health | 5 (3%) | 3 (3%) | 8 (3%) |
| Endocrine and metabolic | 4 (2%) | 2 (2%) | 6 (2%) |
| Anaesthesia and pain control | 3 (2%) | 2 (2%) | 5 (2%) |
| Gastroenterology | 4 (2%) | 1 (1%) | 5 (2%) |
| Skin | 4 (2%) | 1 (1%) | 5 (2%) |
| Respiratory | 4 (2%) | 0 (0%) | 4 (2%) |
| Kidney disease | 3 (2%) | 0 (0%) | 3 (1%) |
| Neonatal care | 0 (0%) | 3 (3%) | 3 (1%) |
| Urology | 2 (1%) | 1 (1%) | 3 (1%) |
| Dentistry and oral health | 1 (1%) | 1 (1%) | 2 (1%) |
| Developmental | 1 (1%) | 1 (1%) | 2 (1%) |
| Ear/ nose/ and throat | 2 (1%) | 0 (0%) | 2 (1%) |
| Genetic disorder | 0 (0%) | 2 (2%) | 2 (1%) |
| Healthcare of older people | 1 (1%) | 1 (1%) | 2 (1%) |
| Rehabilitation | 0 (0%) | 2 (2%) | 2 (1%) |
| Tobacco/ drugs and alcohol dependence | 2 (1%) | 0 (0%) | 2 (1%) |
| Dermatology | 1 (1%) | 0 (0%) | 1 (<1%) |
| Gynaecology | 0 (0%) | 1 (1%) | 1 (<1%) |
| Movement disorders | 0 (0%) | 1 (1%) | 1 (<1%) |
| Muscle diseases | 0 (0%) | 1 (1%) | 1 (<1%) |
| Neurodisability | 0 (0%) | 1 (1%) | 1 (<1%) |
| Public health | 0 (0%) | 1 (1%) | 1 (<1%) |

**Supplementary table 3: Detailed breakdown of COS specifying multiple or multiple interventions or ‘other’ interventions within the scope**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Routine care only (n=164)** | **Routine care and research (n=98)** | **All (n=262)** |
| Multiple interventions | Drug, surgery | 2 (1%) | 0 (0%) | 2 (1%) |
| Surgery, other | 1 (1%) | 1 (1%) | 2 (1%) |
| Health program delivery, telehealth | 1 (1%) | 0 (0%) | 1 (<1%) |
| Surgery, device | 1 (1%) | 0 (0%) | 1 (<1%) |
| Surgery, nursing | 1 (1%) | 0 (0%) | 1 (<1%) |
| Surgery, watchful waiting | 1 (1%) | 0 (0%) | 1 (<1%) |
| Drug, surgery, rehabilitation | 1 (1%) | 0 (0%) | 1 (<1%) |
| Behavioural, drug, surgery, other | 1 (1%) | 0 (0%) | 1 (<1%) |
| Drug, monitoring, surgery | 1 (1%) | 0 (0%) | 1 (<1%) |
| Drug, surgery, other | 1 (1%) | 0 (0%) | 1 (<1%) |
| Drug, surgery, physio, behavioural | 1 (1%) | 0 (0%) | 1 (<1%) |
| Other interventions | Within a given location e.g. all in acute care | 6 (4%) | 0 (0%) | 6 (2%) |
| With a specific aim e.g. all curative interventions | 4 (2%) | 0 (0%) | 4 (2%) |
| Screening | 0 (0%) | 2 (2%) | 2 (1%) |
| Stem cell donation | 0 (0%) | 2 (2%) | 2 (1%) |
| Watchful waiting/ conservative treatment | 1 (0%) | 1(1%) | 2 (1%) |
| Prostate ablation technology | 0 (0%) | 1 (1%) | 1 (<1%) |
| Assisted reproductive technology in mainstream use | 0 (0%) | 1 (1%) | 1 (<1%) |
| Hyperbaric oxygen therapy | 0 (0%) | 1 (1%) | 1 (<1%) |
| Telehealth | 1 (1%) | 0 (0%) | 1 (<1%) |
| Dialysis | 1 (1%) | 0 (0%) | 1 (<1%) |
| Gene therapy | 0 (0%) | 1 (1%) | 1 (<1%) |
| Given by specific people e.g. allied health professionals. | 1 (1%) | 0 (0%) | 1 (<1%) |
| Established interventions | 0 (0%) | 1 (1%) | 1 (<1%) |

**Supplementary table 4: COS developed for use in a single country**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Routine care only**  **n=45** | **Routine care and research**  **n=16** | **All**  **n=61** |
| Iran a | 18 (40%) | 4 (25%) | 22 (36%) |
| Netherlands | 7 (16%) | 2 (13%) | 9 (15%) |
| Canada | 5 (11%) | 1 (6%) | 6 (10%) |
| UK | 3 (7%) | 3 (19%) | 6 (10%) |
| USA | 1 (2%) | 3 (19%) | 4 (7%) |
| China | 3 (7%) | 0 (0%) | 3 (5%) |
| Spain | 2 (4%) | 0 (0%) | 2 (3%) |
| Austria | 1 (2%) | 0 (0%) | 1 (2%) |
| Australia | 1 (2%) | 0 (0%) | 1 (2%) |
| Italy | 1 (2%) | 0 (0%) | 1 (2%) |
| South Korea | 1 (2%) | 0 (0%) | 1 (2%) |
| Spain | 1 (2%) | 0 (0%) | 1 (2%) |
| Ireland | 1 (2%) | 0 (0%) | 1 (2%) |
| Colombia | 0 (0%) | 1 (6%) | 1 (2%) |
| Norway | 0 (0%) | 1 (6%) | 1 (2%) |
| Uganda | 0 (0%) | 1 (6%) | 1 (2%) |

a *Iranian government has recommended the development of Minimum data sets to support structured data collection within their health care system.*

**Supplementary table 5: COS development methods by subgroup**

|  |  |  |  |
| --- | --- | --- | --- |
| **Methods** | **Routine care**  **(n=161)** | **Routine care and research**  **(n=97)** | **All (n=258)***1* |
| **One method only** | **34 (21%)** | **26 (27%)** | **60 (23%)** |
| Delphi | 12 (35%) | 9 (35%) | 21 (35%) |
| Semi structured discussion | 6 (18%) | 6 (23%) | 12 (20%) |
| Consensus development conference | 6 (18%) | 2 (8%) | 8 (13%) |
| Nominal group technique only | 1 (3%) | 3 (12%) | 4 (7%) |
| Systematic review | 1 (3%) | 3 (12%) | 4 (7%) |
| Survey | 3 (9%) | 1 (4%) | 4 (7%) |
| Registry check | 2 (6%) | 2 (8%) | 4 (7%) |
| Focus group | 2 (6%) | 0 (0%) | 2 (3%) |
| Unstructured group discussion | 1 (3%) | 0 (0%) | 1 (2%) |
| **Multiple methods2** | **127 (79%)** | **71 (73%)** | **198 (77%)** |
| Delphi plus other method/s | 92 (72%) | 45 (63%) | 137 (70%) |
| Semi structured discussion plus other method/s | 17 (13%) | 14 (20%) | 31 (16%) |
| Consensus development conference plus other method/s | 5 (4%) | 5 (7%) | 10 (5%) |
| Literature review plus other method/s | 8 (6%) | 7 (10%) | 15 (8%) |
| Nominal group technique plus other method/s | 0 (0%) | 0 (0%) | 0 (0%) |
| Focus group plus other method/s | 2 (2%) | 0 (0%) | 2 (1%) |
| Survey plus other method/s | 2 (2%) | 0 (0%) | 2 (1%) |
| Unstructured discussion plus other method/s | 1 (1%) | 0 (0%) | 1 (1%) |

*Notes1 4 COS did not report methods, 3 for routine care only and one for routine care and research. 2Multiple methods were analysed in a hierarchical manner in order of the methods listed to compare the results with published data from COS for research.*

**Supplementary table 6: Continent of stakeholders involved in COS**

|  |  |  |
| --- | --- | --- |
|  | **Routine care only (n=131) a** | **Routine care and research (n=75) a** |
| N. America | 66 (50%) | 44 (59%) |
| Europe | 87 (66%) | 57 (76%) |
| Australasia | 43 (33%) | 28 (37%) |
| Asia | 64 (49%) | 22 (29%) |
| S. America | 25 (19%) | 18 (24%) |
| Africa | 16 (12%) | 11 (15%) |
| Median [IQR] and range of number of countries b | 1 [1,9], 1-68 | 5 [1,10], 1-97 |

*a 33 COS for routine care and 23 COS for routine care and research did not report sufficient detail to analyse the continents of stakeholders. b 38 COS for routine care and 25 COS for routine care and research did not report sufficient detail to analyse the number of countries.*

**Supplementary table 7: Reporting of methods to improve representativeness:**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **ID** | **Citation** | **Methods** | **Type** | **subgroup** |
| **112** | **Shearsmith 2020** | Option of a paper or online survey | Paper alternative | 1 |
| **129** | **Morris 2014** | Used a central, large venue, considering the use of wheelchairs | Venue | 3 |
| **132** | **Gerritsen 2016** | Offered a paper version alongside the online version | Paper alternative | 3 |
| **149** | **Goncalves 2020** | * Used a card sorting exercise to include those with dementia. * Offered paper and online survey. * The consensus conference used a sample size of up to 15, so that the meeting remained dementia friendly. | Paper alternative plus other | 3 |
| **152** | **Harrop 2020** | Offered paper and online survey | Paper alternative | 3 |
| **187** | **Allin 2019** | So as to represent the full spectrum of clinical and personal experience of gastroschisis, participants were recruited across range of clinical specialties involved in the treatment of children born with gastroschisis and also from families where one or more people had been born with gastroschisis | Sampling method | 3 |
| **204** | **Canete 2020** | To obtain representatives of the different phenotypes within the health condition, patients were selected based on their sociodemographic (age and sex) and clinical characteristics (joint disease and skin manifestations, time since diagnosis, time since treatment onset). | Sampling method | 1 |
| **238** | **Nelson 2018** | The survey for people living with dementia was designed to be accessible in its layout and use of language. As much as possible, we avoided use of technical language so then the surveys are accessible to all. Efforts were made to ensure wide reach with distribution in memory clinics and via postal survey to enable us to extend our reach among hard-to-reach stakeholders or those who do not have internet access. The surveys were distributed in English, Spanish, and Catalan, but not other European languages, which may have affected the response rates and the generalisability of the responses. With a nonprobability sampling method, sample populations may or may not represent the target populations. | Paper alternative plus other | 3 |

**Supplementary table 8: Methods for engaging patient stakeholders within COS development**

|  |  |  |  |
| --- | --- | --- | --- |
| **Methods1** | | | **Number of COS**  **(n=112)** |
| Activities patients / patient representatives were involved in | Online survey or Delphi | | 61 (54%) |
| Online meeting | | 39 (35%) |
| Face to face meeting | | 36 (32%) |
| Paper survey or Delphi | | 9 (8%) |
| Face to face survey or Delphi | | 5 (4%) |
| How patients / patient representatives were identified | No methods reported | | 41 (37%) |
| Where methods reported (n=71) | Patient organisations | 46 (65%) |
| Health care setting | 24 (34%) |
| Snowball sampling | 9 (13%) |
| General advertising | 9 (13%) |
| Community outreach | 5 (7%) |
| Civic records | 0 (0%) |
| Other e.g. research groups, personal recommendation | 6 (5%) |
| Methods used to invite patients / patient representatives | No methods reported | | 80 (71%) |
| Where methods reported (n=32) | Email | 15 (47%) |
| Face to face contact | 12 (38%) |
| Social media | 11 (34%) |
| Letter | 4 (13%) |
| Telephone | 2 (6%) |
| Other e.g. posters, website | 5 (16%) |

1 *COS were classified according to all relevant categories*