**Supplementary information. Workshop 1-4 Attendance**

|  |  |  |  |
| --- | --- | --- | --- |
| **NAME** | **PROFESSIONAL ROLE** | **EXPERIENCE IN THE FIELD OF CRPS****(YEARS)** | **WORKSHOP ATTENDED** |
| **CLINICAL** | **SCIENTIFIC** | **1** | **2** | **3** | **4** |
| Birklein, Frank  | Clinical Academic | ≥21  | ✓ | ✓ | ✓ |  |
| Bruehl, Stephen | Clinical Academic | ≥21 |  |  | ✓ | ✓ |
| Brunner, Florian | Clinical Academic | 11-20 |  |  | ✓ | ✓ |
| Burbridge, Claire | Industry – Pain and Patient Reported Outcomes | 6-10 | ✓ |  |  |  |
| Carey, William | Industry  | 6-10 |  | ✓ |  |  |  |
| Davies, Lindsay | Academic |  | 0-5 | ✓ | ✓ | ✓ | ✓ |
| Gobeil, Francois  | Clinical  | 6-10 |  | ✓ | ✓ | ✓ | ✓ |
| Grieve, Sharon | Academic | 6-10 |  | ✓ | ✓ | ✓ | ✓ |
| Hall, Jane | Clinical | 6-10 |  | ✓ |  |  |  |
| Haigh, Richard | Clinical Academic | 11-20 |  |  | ✓ | ✓ |  |
| Harden, Norman | Academic | ≥21 | ✓ | ✓ |  | ✓ |
| Holly, Janet | Clinical | ≥21 |  | ✓ | ✓ | ✓ | ✓ |
| Howard, Claire | Clinical | 0-5 |  | ✓ |  |  |  |
| Kirsling, Amy | Academic | N/A | N/A |  | ✓ | ✓ | ✓ |
| Knudsen, Lone | Clinical Academic |  | 6-10 |  |  | ✓ |  |
| Lewis, Jennifer | Clinical Academic | 11-20 | ✓ | ✓ |  | ✓ |
| Llewellyn, Alison | Academic |  | 0-5 | ✓ |  |  |  |
| Marinus, Johan | Academic |  | 11-20 | ✓ |  |  |  |
| McCabe, Candida | Clinical Academic | 11-20 | ✓ | ✓ | ✓ | ✓ |
| Moskovitz, Peter | Clinical | ≥21 |  | ✓ | ✓ | ✓ |  |
| Neugebauer, Martina | Clinical | 11-20 |  | ✓ |  |  |  |
| Packham, Tara | Clinical Academic | ≥21 | 6-10 |  | ✓ | ✓ | ✓ |
| Perez, Roberto  | Academic |  | ≥21 | ✓ | ✓ | ✓ | ✓ |
| Reiners, Anselm | Clinical | ≥21 | 11-20 | ✓ |  |  |  |
| Rocha, Roberto | Clinical | 11-20 |  | ✓ |  |  |  |
| Schlereth, Tanja | Clinical Academic | 11-20 |  |  |  | ✓ |
| Terkelsen, Astrid | Clinical Academic | 0-5 | 6-10 | ✓ |  |  | ✓ |
| Vatine, Jean-Jacques | Clinical Academic | ≥21 | ✓ |  |  | ✓ |
| Worth, Tina | Industry |  | 0-5 | ✓ |  | ✓ |  |
| Patient representatives  | Number at each workshop | 5 | 1 | 5 | 3 |

**IASP Pain and the Sympathetic Nervous System SIG**

**A multi-centre international collaboration for the development and implementation of a Minimum Core Data set of outcome measures for**

**Complex Regional Pain Syndrome clinical studies**

**Workshop 1**

November 19th 2013

Royal National Hospital for Rheumatic Diseases,

Bath, UK

**AGENDA**

|  |  |
| --- | --- |
| 9.30-10.00AM | **Registration and Coffee** |
| 10.00-10.15 | **Introduction - Professor Candy McCabe, Bath, UK** Royal National Hospital for Rheumatic Diseases,  Bath, UK* Welcome, introductions.

Guiding principles for meeting. Overview of project and introduction to existing initiatives in other conditions.The key objective for the meeting: to define a key question/s upon which the initial study will be based. |
| 10.15-11.30 | **Discussion on submitted Scope and Research suggestions*** Form small working groups comprising members representing clinical, academic, patient and industry to discuss and agree on five priority research questions using data submitted from members of the group prior to the meeting, under the headings;

1)Identification of Risk Factors2)Clinical Course – Development of condition3)Clinical Course – Outcomes4)Clinical Course – Response to therapy5)Clinical Course – Condition SeverityReport back |
| 11.30-12.15 | **Prioritisation of questions*** Whole group discussion.
* Group vote on proposed questions to refine options.
 |
| 12.15-1.00PM | **CRPS Severity Score (CSS) - Professor Norman Harden**  Rehabilitation Institute of Chicago, USA * Presentation on current use of CSS
 |
| 13.00-13.30 | **Lunch** |
| 13.30-14.30 | **Domain selection (and possibly instruments)** **for top priority questions*** Small group discussion on domain selection.
 |
| 14.30-15.30 | **Plenary feedback - comparison of domains**Seek common ground, reach consensus on which become the core domains. |
| 15.30-17.0017.00  | **Discussion of the way forward*** Group discussion on implementation plan/practicalities.
* Consider possible need for creation of small working groups for further deliberations via email both with attendees and wider group.
* Consider need for additional face to face meeting and interim teleconferences.
* Funding options.
* Circulate documentation from meeting to wider consortium for feedback.

 **Close** |

**Core Outcome Measures for complex regional PAin syndrome Clinical sTudies**

**(COMPACT)**

**Workshop 2**

 May 15th 2014

Chicago, Illinois, USA

**AGENDA**

|  |  |  |
| --- | --- | --- |
| 8.30AM | **Breakfast** |  |
| 9.00 | **Welcome** | **Professor Candy McCabe**,Royal National Hospital for Rheumatic Diseases, Bath, UK |
| 9.15 | **Summary of first workshop** Key Objectives of the meeting:* To identify 5-6 instruments to be used as the first draft core outcome measurement set. Crucial to get a consensus of ‘buy in’ and that this draft should not be agreed ‘at any cost’.
* To agree if instruments should be generic or CRPS specific.
* To be informed by existing models (OMERACT, IMMPACT as gold standard).
* To revisit research question defined at Workshop 1. Reach further consensus on refined question.
 |  |
| 9.45 | **Outcome measures used in CRPS intervention studies:** **a review of the literature** * Presentation on findings of literature review carried out following Workshop 1.
* Circulate resulting documentation for group discussion.
* Establish group consensus that literature review is sufficiently robust to move forward.
 |  **Sharon Grieve** Clinical Research Nurse, Royal National Hospital for  Rheumatic Diseases,  Bath, UK |
| 10.15 | **Measurement properties of assessments for CRPS:** **a systematic review** * Presentation of systematic review.
 |  **Tara Packham** Occupational Therapist, McMaster University,  Hamilton, Canada |
| 10.45 | **Discussion** |  |
| 11.00 | **Coffee** |  |
| 11.20 | **Identifying outcome measures to capture data for each domain*** Form two workgroups, in order to discuss and form ideas/agreement on the key domains, required to answer the research question.
 |  |
| 12.15 | **Feedback** * Summarise combined/overlapping domains resulting from two workgroups.
 |  |
| 12.30 | **Lunch** |  |
| 13.15 | **Outcome measures - cultural challenges** * Presentation to establish and agree consistent,

 ‘best practice’ process for any future translations. |  **Lindsay Davies** Royal National Hospital for  Rheumatic Diseases,  Bath, UK |
| 13.45  | **Establishing consensus on core outcome measures*** Whole group discussion around possible OM’s.
 |  |
| 14.30 | **The next steps*** Where do we go from here?
* Funding.
* Any other business.
 |  |
| 15.00 | **Coffee and Close****AGENDA** **(COMPACT) Workshop 3**January 13th and 14th 2015Bath, UK |  |

DAY 1

2.00PM **Welcome - Professor Candy McCabe**

 Royal National Hospital for Rheumatic Diseases, Bath, UK

2.15 **COMPACT summary to date - Professor Candy McCabe**

* The key objective of the meeting: to agree 5-6 pieces of data/instruments to be used

 as the draft COMPACT.

2.45 **Questionnaire Models: process and feedback - Sharon Grieve**

 Royal National Hospital for Rheumatic Diseases,

 Bath, UK

* Presentation on the rationale, process and results of a questionnaire modelling exercise,

 including feedback and vote results provided by the consortium by email, prior to the

 meeting.

3.15 **Discussion**

* Whole group discussion around proposed four questionnaire models and results of

 previous consortium vote.

* Whole group vote on what is considered essential.

3.45 **Coffee**

4.00 **PROMIS/CHOIR overview - Professor Stephen Bruehl**

 Vanderbilt University School of Medicine,

 Nashville, USA

* Presentation on PROMIS/CHOIR, as possible data capture /storage option.

 **Industry Perspective - Tina Worth,**

Grunenthal Ltd.

* Presentation on industry perspective, when considering a draft core measurement set.

4.30 **Goals for Workshop Day 2 - Professor Candy McCabe**

* Whole group discussion/consensus on guiding principles (based on all discussions to date)

 for drafting COMPACT.

5.00 **Close**

6.00 **Supper**

DAY 2 (14th January)

9.00AM **Coffee**

9.30 **Welcome and plan for day - Professor Candy McCabe**

9.45 **Group work to determine draft core measurement set**

* Form three small workgroups, in order to debate and form ideas/agreement on a first

 draft COMPACT.

* Set out guiding principles for these discussions, including a group vote on the use of

 PROMIS items.

10.45 **Break**

11.00 **Feedback from groups and summary**

* Three workgroups to report back with rationales for their chosen draft COMPACT,

 including total number of items.

12.00 **Lunch**

1.00PM **Discussion on finalising first core measurement set**

* Whole group discussion on particular aspects arising from the group work.
* Summary of findings.

2.00 **Data collection options - Professor Candy McCabe/Sharon Grieve**

* Presentation on options for data collection.
* Consideration to be given to;
* Patient burden
* Layout/design
* Instructions for use

2.30 **Translation/ethical issues - Lindsay Davies**

 Royal National Hospital for Rheumatic Diseases,

 Bath, UK

* Presentation to reiterate previously agreed translation process for future COMPACT

 translations across the consortium.

* Establish agreement on ethics approval.

3.00 **Break**

3.15 **Update on International Research Consortium - Amy Kirsling**

Director of Operations,

International Research Consortium for CRPS

 USA

* Presentation on potential management/governance of COMPACT.
	1. **Dissemination of COMPACT and acknowledgements - Professor Candy McCabe**

 Whole group discussion around;

* Potential abstract opportunities.
* Authorship and Publications.
* Need for a generic term for COMPACT group.
* Acknowledgement of use within personal publications.

4.15 **Next steps and timeline for implementation of COMPACT**

* Discussion and consensus on data capture time points.
* Agreement of next meeting date/venue.

5.00 **Close**

**Core Outcome Measures for complex regional PAin syndrome Clinical sTudies**

**(COMPACT)**

**Workshop 4**

August 29th and 30th 2015

 Balgrist University Hospital

 Zurich, Switzerland

 **AGENDA**

DAY 1

3.00PM **Welcome - Professor Candy McCabe**

Royal National Hospital for Rheumatic Diseases, Bath, UK

* The key objective of the meeting: To reach a consensus on a final draft COMPACT,

 based upon previous workshop discussions.

3.05 **COMPACT: a summary to date and revisiting the domains -**

 **Professor Candy McCabe and Sharon Grieve**

* Summary of discussions/agreements as a result of Workshops 1-3.

 **Discussion**

* Revisit the 7 current core domains to ensure that all agree that these remain fully

 justified in the proposed current working draft COMPACT.

* Revisit and reach consensus on the final inclusion of each domain, to ensure that

 this can be robustly documented and demonstrated in any future publications.

4.30 **Break**

4.45 **Rasch analysis of PainDETECT - Tara Packham**

 Occupational Therapist

 McMaster University,

 Hamilton, Canada

* Presentation demonstrating Rasch Analysis as a strategy for examining the

 psychometric properties of a measurement scale, based in item response theory.

5.15 **Discussion**

* 1. **Goals for workshop Day 2 – Professor Candy McCabe**
* Reach consensus on first full draft COMPACT.

6.00 **Close**

7.00 **Supper**

DAY 2 (30th August)

9.30AM **Coffee**

9.45 **Welcome and plan for day – Professor Candy McCabe**

9.50 **Core Measurement Set: First draft and feedback from focus group - Sharon Grieve**

Royal National Hospital for Rheumatic Diseases, Bath, UK

* Presentation of first draft COMPACT, based upon discussions/agreements at

Workshops 1-3

* Presentation of findings from patient focus group held in Bath, following Workshop 3 and prior to Workshop 4.
* Report changes made to draft version of COMPACT after Workshop 3, as a result of the focus groups.

10.30 **Break**

10.45 **First draft Core Measurement Set - review (group work)**

* Three workgroups to debate and form ideas/consensus on the presented first full draft version of COMPACT.
* Following workgroup discussions, each individual item in COMPACT to be discussed amongst the entire working group.
* As a result of group work, current draft COMPACT to be updated, according to agreed amendments and recirculated to entire consortium for final approval.

12.00 **Lunch**

1.00PM **Using REDCap to collect multisite assessment data - Professor Stephen Bruehl**

Vanderbilt University School of Medicine, Nashville, USA

* Presentation on ‘Using REDCap to collect Multisite Assessment Data’.

1.20 **Discussion**

1.40 **The practicalities of COMPACT - Professor Candy McCabe/Sharon Grieve**

* Group discussion establishing study practicalities, within the context of usingREDCap as

a data capture tool.

2.30 **Break**

3.00 **Dissemination of COMPACT - Professor Candy McCabe/Sharon Grieve**

* Group discussion on timeframe and method of publications.

3.30 **Next steps and timeline for implementation of COMPACT**

* Group discussion/agreement on next steps, including suggestions for next meeting.

4.30 **Close**

Supplementary information:

**Summary table of questionnaire outcome measures considered for potential inclusion in the final COMPACT**

|  |  |  |
| --- | --- | --- |
| **Domain** | **Questionnaire Outcome Measure** | **Reference** |
| Pain | Visual analogue scale |  |
| Numeric rating scale |  |
| Short-Form McGill Pain Questionnaire  | Dworkin et al (2009) |
| Pain Detect | Freynhagen et al (2006) |
| Pain Disability Index | Pollard (1984) |
| Brief Pain Inventory  | Cleeland, (1989). |
| PROMIS items | Cella et al (2007) for PROMIS 29 |
| Pain QuILT | Lalloo et al (2014) |
| Michigan body map | Brummett et al (2016) |
| Disease severity | CRPS Severity Score | Harden et al (2010) |
| Participation and function | SF-36 | Ware andSherbourne (1992) |
| Radboud Skills Questionnaire | Oerlemanset al (2000), |
| Disabilities of Arm,Shoulder and Hand questionnaire | Hudak et al.,(1996) |
| Walking Ability Questionnaire | Roorda et al (2005) |
| Euroqol-5D | EuroQol Group(1990) |
| PROMIS items | Cella et al (2007) for PROMIS 29 |
| Emotional and psychological function | Beck Depression Inventory | Beck et al 1961 |
| Tampa Scale for Kinesiophobia | Miller et al.,(1991). |
| Zung Depression Scale | Zung (1965) |
| State Trait Anxiety Scale | Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, (1983) |
| Hospital Anxiety and Depression Scale (HADS) | Zigmond and Snaith(1983) |
| Centre for EpidemiologicStudies Depression Scale | Radloff (1977) |
| Patient Health Questionnaire (PHQ-9) | Spilzer et al (1999) |
| PROMIS items | Cella et al (2007) for PROMIS 29 |
| Self Efficacy | Pain Self Efficacy Questionnaire | Nicholas (2007) |
| Impact on Participation and Autonomy Questionnaire | Cardol et al (1999) |
|  | Pain Coping Inventory | Kraaimaat and Evers (2003) |
| Catastrophizing | Pain Catastrophizing Scale | Sullivan et al (1995) |
| Patients Global Impression of Change  | Patients Global Impression of Change questionnaire |  |
| Global perceived effect |  |

**References**

Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh, J. An inventory for measuring depression. Archives of General Psychiatry1961; 4, 561-571

Brummett C, Bakshi R, Goesling J, Leung D, Moser S, Zollars J, Williams D, Clauw D, Hassett A. Preliminary validation of the Michigan Body Map. Pain 2016;157 (6), 1205-1212

Cardol M, de Haan RJ, van den Bos GA, de Jong BA, de Groot IJ. The development of a handicap assessment questionnaire: The impact on participation and autonomy (IPA). Clin Rehabil 1999; 13(5), 411–419

Cella D, Yount S, Rothrock N, Gershon R, Cook, K, Reeve B, Ader D, Fries JF, Bruce B, Matthias R, & on behalf of the PROMIS cooperative group. [The Patient Reported Outcomes Measurement Information System (PROMIS): Progress of an NIH Roadmap Cooperative Group during its first two years](https://web.nhs.net/OWA/redir.aspx?SURL=vC33mW0yWVG7kEhsjTECWT7Aw-0hH0-HDflzmp3l6Un1u3PMOX7TCGgAdAB0AHAAOgAvAC8AdwB3AHcALgBuAGMAYgBpAC4AbgBsAG0ALgBuAGkAaAAuAGcAbwB2AC8AcAB1AGIAbQBlAGQALwAxADcANAA0ADMAMQAxADYA&URL=http%3a%2f%2fwww.ncbi.nlm.nih.gov%2fpubmed%2f17443116). Med Care 2007; 45(5), S3-11. (PMID: 17443116)

Cleeland, C. Measurement of pain by subjective report. In Chapman C, Loeser J, editors. Issues

in Pain Management, New York: Raven. 1989. pp. 391–403

Dworkin RH, Turk DC, Revicki DA, Harding G, Coyne KS, Peirce-Sandner S, Bhagwat D, Everton D, Burke LB, Cowan P, Farrar JT, Hertz S, Max MB, Rappaport BA, Melzack R. Development and initial validation of an expanded and revised version of the Short-form McGill Pain Questionnaire (SF-MPQ-2). Pain 2009;144(1-2), 35-42

Euroqol Group. EuroQol – A new facility for the measurement

of health-related quality of life. Health Policy 1990;16: 199–208

Freynhagen R, Baron R, Gockel U, Tölle TR. painDETECT: a new screening questionnaire to identify neuropathic components in patients with back pain. Curr Med Res Opin 2006; 22(10), 1911–1920.

Harden RN, Bruehl S, Perez RSGM, Birklein F, Marinus J, Maihofner C, Lubenow T, Buvanendran A, Mackey S, Graciosa J, Mogilevski M, Ramsden C, Schlereth T, Chont M, Vatine JJ. Development of a severity score for CRPS. Pain 2010; 151(3): 870-876

Hudak P, Amadio P, Bombardier C. The Upper Extremity Collaborative Group. Development of an upper extremity outcome measure: The DASH (Disabilities of the Arm, Shoulder, and Hand)

[corrected]. Am J Ind Med1996; 29, 602–608.

Kraaimaat FW, Evers AW. Pain-coping strategies in chronic pain patients: psychometric characteristics of the pain-coping inventory (PCI). Int J Behav Med. 2003;10(4):343-63.

Lalloo C, Kumbhare D, Stinson JN, Henry JL. Pain-QuILT: Clinical Feasibility of a Web-Based Visual Pain Assessment Tool in Adults With Chronic Pain. J Med Internet Res 2014;16(5):e127

Miller R, Kori S, Todd D. The Tampa Scale: A measure of kinisophobia. Clin J Pain 1991; 7, 51–52.

Nicholas MK. The pain self-efficacy questionnaire: Taking pain into account. Eur J Pain. 2007;11(2), 153-163.

Oerlemans H, Cup E, de Boo T, Goris R, Oostendorp R. The Radboud skills questionnaire: Construction and reliability in patients with reflex sympathetic dystrophy of one upper extremity. Disabil Rehabil 2000; 22, 233–245.

Pollard CA. Preliminary validity study of the Pain Disability Index. Perceptual and Motor Skills 1984; 59, 974–974.

Radloff L. The CES-D scale: a self report depression scale for research in the general population. Applied Psychological Measurement 1977;1:385–401.

Roorda L, Roebroeck M, Van Tilburg T, Molenaar I, Lankhorst G, Bouter L, Boonstra A, De Laat F, Caron J, Burger B. Measuring activity limitations in walking: Development of a

hierarchical scale for patients with lower-extremity disorders who live at home. Arch Phys Med Rehabil 2005; 86, 2277–2283.

Spielberger CD, Gorsuch RL, Lushene R, Vagg PR, Jacobs GA. (1983). Manual for the State-Trait Anxiety Inventory. Palo Alto, CA: Consulting Psychologists Press

Spitzer RL, Kroenke K, Williams JBW. Patient Health Questionnaire Study Group. Validity and utility of a self-report version of PRIME-MD: the PHQ Primary Care Study. JAMA.  1999; 282:1737–44.

Sullivan ML, Bishop SR, Pivik J. The Pain Catastrophizing Scale: Development and validation. Psychological Assessment 1995; *7*(4), 524-532

Ware J, Sherbourne C. (1992). The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care 1992; 30, 473–483.

Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. Acta Psychiatr Scand 1983;67:361-370

Zung WW. A self rating depression scale. Arch Gen Psychiatry 1965; 12:63-