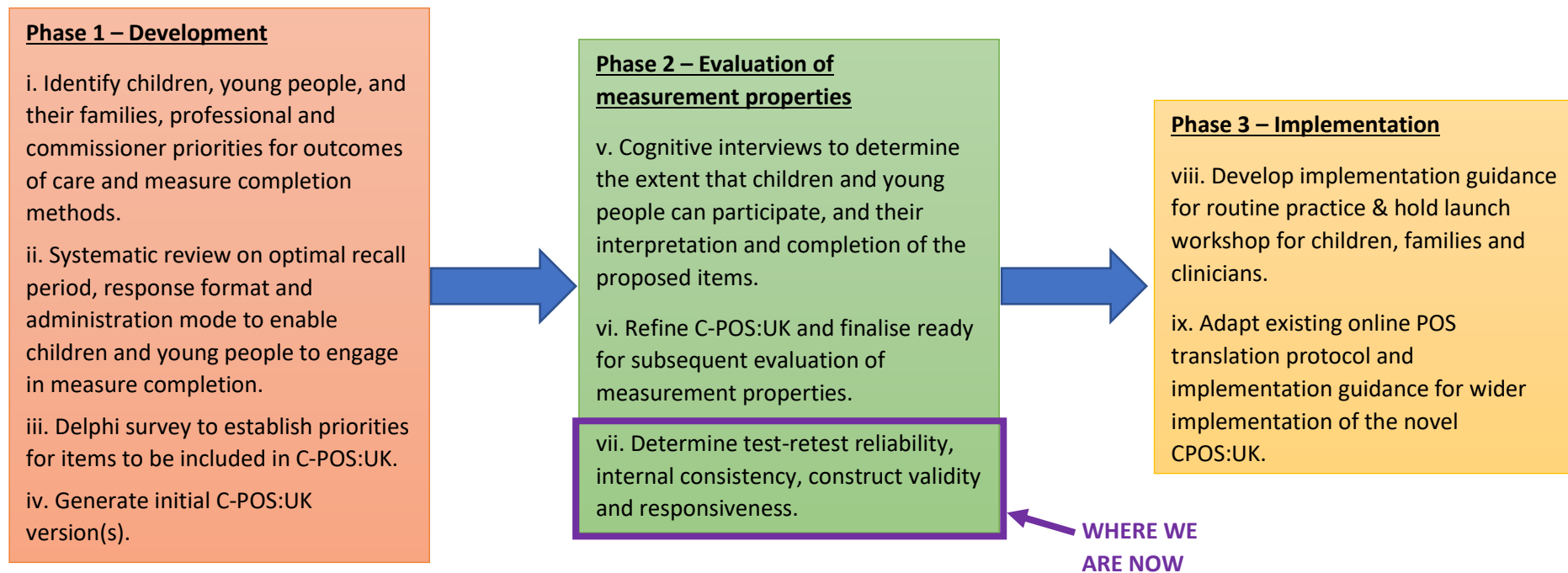


C-POS SUMMARY

C-POS:UK is being developed especially for children and young people with a variety of life-limiting and life-threatening conditions. The short tool measures symptoms and concerns of these children and young people and those of their families, and is intended for use in clinical care, and will also be useful for research studies.

The development of C-POS:UK began following a systematic literature review that identified there was no ideal measure for use with this varied population. A robust development process is being followed including a qualitative interview study, systematic review on how to best involve children and young people, survey to prioritise topics to include, and an expert meeting to develop measure items. The preliminary version was tested and refined via cognitive interviews.

C-POS:UK is currently undergoing robust development through evaluation of measurement properties in a large national study with approximately 70 clinical sites. The team are testing the measure to ensure it is working as it should. The figure below represents the process of outcome measure development that the C-POS:UK team are undertaking. The measure will not be available for use until this robust work has concluded. This will ensure that upon completion, the C-POS:UK can be used and adapted with confidence.



Use of C-POS:UK is not encouraged until the above phases are complete. It will not be available for cultural adaptation before psychometric evaluation of measurement properties and analysis is finished.

The principal investigator is Professor Richard Harding. You can find out more about the project team here: <https://www.kcl.ac.uk/research/c-pos>

Papers published by the C-POS:UK team, by corresponding phase

(pre study, establishing the basis for C-POS)

- Coombes, L. H., Wiseman, T., Lucas, G., Sangha, A., & Murtagh, F. E. (2016). Health-related quality-of-life outcome measures in paediatric palliative care: A systematic review of psychometric properties and feasibility of use. *Palliative Medicine*, 30(10), 935-949. <https://doi.org/10.1177/0269216316649155>
- Harding, R., Chambers, L., & Bluebond-Langner, M. (2019). Advancing the science of outcome measurement in paediatric palliative care. *International Journal of Palliative Nursing*, 25(2), 72-79. <https://doi.org/10.12968/ijpn.2019.25.2.72>

Phase 1

- i. Coombes, L., Braybrook, D., Roach, A., Scott, H., Harðardóttir, D., Bristowe, K., Ellis-Smith, C., Bluebond-Langner, M., Fraser, L. K., Downing, J., Farsides, B., Murtagh, F. E. M., Harding, R., & on behalf of, C.-P. (2022). Achieving child-centred care for children and young people with life-limiting and life-threatening conditions—a qualitative interview study. *European Journal of Pediatrics*, 181(10), 3739-3752. <https://doi.org/10.1007/s00431-022-04566-w>

Scott, H. M., Coombes, L., Braybrook, D., Roach, A., Harðardóttir, D., Bristowe, K., Ellis-Smith, C., Higginson, I., Gao, W., Bluebond-Langner, M., Farsides, B., Murtagh, F. E. M., Fraser, L. K., & Harding, R. (2022). COVID-19: Impact on Pediatric Palliative Care. *Journal of Pain and Symptom Management*, 64(1), e1-e5. <https://doi.org/10.1016/j.jpainsymman.2022.02.330>

Scott, H. M., Coombes, L., Braybrook, D., Roach, A., Harðardóttir, D., Bristowe, K., Ellis-Smith, C., Downing, J., Murtagh, F. E. M., Farsides, B., Fraser, L. K., Bluebond-Langner, M. & Harding, R. (2023) Spiritual, religious, and existential concerns of children and young people with life-limiting and life-threatening conditions: A qualitative interview study. *Palliative Medicine*. [online first] <https://doi.org/10.1177/02692163231165101>
- ii. Coombes, L., Bristowe, K., Ellis-Smith, C., Aworinde, J., Fraser, L. K., Downing, J., Bluebond-Langner, M., Chambers, L., Murtagh, F. E. M., & Harding, R. (2021). Enhancing validity, reliability and participation in self-reported health outcome measurement for children and young people: a systematic review of recall period, response scale format, and administration modality. *Quality of Life Research*, 30(7), 1803-1832. <https://doi.org/10.1007/s11136-021-02814-4>
- iii. Delphi survey informed by i. Coombes et al. (2022) (see above); and Namisango et al. (2019) systematic review (see below, international C-POS work)

Additional C-POS:UK publications

- Scott, H. M., Coombes, L., Braybrook, D., Harðardóttir, D., Gackowska, I., & Harding, R. (2023). Knowledge, attitudes and beliefs about paediatric palliative care. *Annals of Palliative Medicine*, 12(1), 10-12. <https://doi.org/10.21037/apm-22-1326>

International work on C POS

- **APCA C-POS**

The C-POS team are working with the African Palliative Care Association (APCA) to refine APCA C-POS.

Use of APCA C-POS is not encouraged and additional versions will be developed once the core measures are fully validated.

- **Other international development work**

Work is underway in the Middle East, Australasia and Asia to further test and develop C-POS measures.

Papers published in collaboration with international C-POS teams

- **APCA C-POS**

Namisango, E.,K. Bristowe,F.E. Murtagh,J. Downing,R.A. Powell,M. Abas,L. Lohfeld,Z. Ali,M. Atieno,D. Haufiku,S. Guma,E.B. Luyirika,F.N. Mwangi-Powell,I.J. Higginson,and R. Harding, Towards person-centred quality care for children with life-limiting and life-threatening illness: Self-reported symptoms, concerns and priority outcomes from a multi-country qualitative study. *Palliative Medicine*, 2020. 34(3). <https://doi.org/10.1177/0269216319900137>

Namisango, E.,K. Bristowe,M.J. Allsop,F.E.M. Murtagh,M. Abas,I.J. Higginson,J. Downing,and R. Harding, Symptoms and Concerns Among Children and Young People with Life-Limiting and Life-Threatening Conditions: A Systematic Review Highlighting Meaningful Health Outcomes. *The Patient - Patient-Centered Outcomes Research*, 2019. 12(1). <https://doi.org/10.1007/s40271-018-0333-5>

- **Towards developing C-POS in the Middle East**

Boufkhed, S.,S. Yurduşen,G. Alarjeh,F. Ahmed,W. Alrjoub,P. Guo,S. Alajarmeh,M. Şengelen,M. Cemaloğlu,B. Aydın,A. Alnassan,S. Al-Awady,T. Kutluk,O. Shamieh,and R. Harding, Concerns and priority outcomes for children with advanced cancer and their families in the Middle East: A cross-national qualitative study. *Frontiers in Oncology*, 2023. 13. <https://doi.org/10.3389/fonc.2023.1120990>

