Development of a Core Outcome Set for Evaluating the Effectiveness of Adult Palliative Care Services in Wales

End of Study Summary Report

July 2022

This report presents a summary of the results of a consensus-driven, multi-stage project to identify and agree on a Core Outcome Set (COS) for evaluating the effectiveness of adult palliative care services in Wales.

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TABLE OF CONTENTS

EXECUTIVE SUMMARY

Assessment of palliative care delivery is essential for managing service performance and improvement in care. However, palliative care delivery assessments have traditionally looked at service activity, rather than the impact of those services on patient/family outcomes. There is increasing emphasis and international agreement on the need for outcome measures/domains which look at the quality and effectiveness of palliative care services, rather than just service activity. In Wales, the End-of-Life Board (EoLB) has prioritised the development of a consistent approach to the collection of data, specifically on the quality and effectiveness of palliative care services for patients and families. Several national/international initiatives have successfully applied their own standard outcome measurement systems at local levels. This project therefore focused on reaching an agreement on outcomes relevant to adult palliative care services in Wales.

This project was a multi-stage study to identify those effectiveness outcomes for adult palliative care services that are most important to capture in Wales, consisting of four stages:

1. Stage I: Rapid Review of existing literature – a rapid review was conducted to identify outcomes already used in the UK and internationally to measure palliative care service quality, specifically effectiveness.
2. Stage II: Expert workshop – a meeting with a variety of individuals with professional experience of working with or within palliative care services in Wales (healthcare professionals, non-clinical staff working in a managerial role in a palliative care setting and third sector representatives). The purpose of this stakeholder meeting was to examine the list of concepts identified in the literature review and to consider whether there were a) any concepts included that did not meet the definition of an 'effectiveness outcome', b) any concepts that could be deduplicated/combined due to being similar and c) any concepts that were missing and should be added to the list at this stage. In addition, workshop participants were asked to reflect on time points for measuring the outcomes (i.e. 'when' to measure). This process allowed the development of a refined longlist of suggested outcomes for consideration by a wider group of stakeholders in an online survey.
3. Stage III: All Wales Ranking Survey: The longlist generated from Stages I and II was reviewed by a broader range of stakeholders from across Wales to prioritise those outcomes felt to be most important in assessing effectiveness of palliative care interventions. A structured approach was then used to identify how the ratings of perceived importance translated into a consensus for individual outcomes to be included in a final core outcome set.

4. Stage IV: Final Expert group meeting - a final meeting was convened with a group of professionals with experience of working either within or with palliative care services in Wales to consider the outcomes of the survey, to discuss any remaining uncertainties and to vote on and confirm the final core outcome set. In addition, the expert group was asked to discuss next steps for the implementation of the agreed-upon core outcome set, i.e. establishing to what extent existing outcome measurement toolkits may capture the identified outcomes, whether there might be any gaps and considering how the core outcome set will best be aligned with the assessments of other quality of care dimensions (e.g. service efficiency, safety and patient experience).

The four-stage approach resulted in a final core outcome set for the evaluation of the effectiveness of adult palliative care services in Wales that consists of 21 outcomes, grouped into 6 domains, as summarised in Table 1.

Table 1: Final core outcome set of 21 outcomes across 6 domains to be recommended to the EoLB for the evaluation of the effectiveness of palliative care services in Wales

DOMAIN	OUTCOMES
Physical aspects of care	Pain
	Breathlessness
	Fatigue
	Nausea
	Vomiting
	Dry and/or sore mouth
	Sore mouth
	Constipation
	Loss of appetite
	Performance status
	Activities of Daily Living (Basic)
	Activities of Daily Living (Instrumental)
Psychological aspects of care	Psychological needs and distress
	Depression
	Anxiety
	Agitation
	Cognitive function
Social aspects of care	Family wellbeing
	Family carer impact
Spiritual aspects of care	Feeling at peace
Overall wellbeing	Quality of life
Information and preferences	Information and communication needs
Total: 21 outcomes across 6 domains	

The results of this study will underpin the End-of-Life Board’s judgement on a future outcome measurement dataset for Wales. The discussions in the final expert meeting (Stage IV) highlighted the importance of embedding the implementation of such a core outcome set within existing NHS systems/processes and of incorporating it within the wider approach of capturing all dimensions of care service quality.

ABBREVIATIONS AND GLOSSARY

AHP	Allied Health Professional
COMET	Core Outcome Measures in Effectiveness Trials
COS	Core Outcome Set
DHCW	Digital Health and Care Wales
EoLB	End of Life Care Board in Wales
GP	General practitioner
ICD-11	International Classification of Diseases 11th Revision
HNA	Holistic Needs Assessment
MCPCRC	Marie Curie Palliative Care Research Centre
NGT	Nominal Group Technique
NHS	National Health Service
NICE	The National Institute for Health and Care Excellence
OACC	Outcomes Assessment and Complexity Collaborative
PaCERS	Palliative Care Evidence Review Service
PCOC	Palliative Care Outcome Collaboration
PRO-CTCAE	Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events
SoMREC	School of Medicine Research Ethics Committee
SPC	Specialist Palliative Care
SURE	Specialist Unit for Review Evidence
WCRC	Wales Cancer Research Centre
WHO	World Health Organisation
WViHC	Wales Value in Health Centre

1 INTRODUCTION

1.1 BACKGROUND AND RATIONALE

The NICE Quality Standard for End-of-Life Care for Adults sets out key elements for high quality service delivery in the UK [1]. Regular and consistent assessment of care delivery is essential for managing service performance and driving improvements in care [2]. Traditionally such assessments have tended to focus on capturing process related outcomes (service volume, response times etc) to demonstrate service activity, rather than regularly measuring impact of services on patient and family outcomes.

More recently, there has been increasing emphasis – and international consensus – on the need for outcomes which focus more specifically on impact, in particular on domains of quality such as effectiveness and efficiency of care [3,4].

Given the complexity of palliative care patient and caregiver needs, which will change over time and include multi-dimensional aspects of care, defining appropriate outcomes in this context can be challenging. However, there have recently been several initiatives to standardise approaches to this type of outcome assessment and to encourage regional approaches which will meet local needs but also allow benchmarking nationally and internationally [5,6].

The European Association of Palliative Care has previously published a White Paper on the topic [7] – with recommendations – and there have also been two national, interlinked initiatives of note. The Outcomes Assessment and Complexity Collaborative (OACC) in England [8] has successfully established a standardised patient-level outcome set, which is used by over 200 services. The more established Palliative Care Outcome Collaboration (PCOC) in Australia [9] has been collecting standardised patient focused outcomes for over a decade and incorporates over 120 services in its network.

In Wales, the End-of-Life Care Board (EoLB) has prioritised the need to establish a standardised approach to the collection of this type of data set. The first goal is to establish a consensus on core effectiveness outcomes and to subsequently identify whether an existing approach such as OACC or PCOC may meet Wales' needs, or whether the specific health and social care economy unique to Wales mandates for additional or different domains of care to be addressed. This core outcome set (COS) will then sit alongside measures of efficiency, patient experience and safety in reflecting the overall quality of adult palliative care delivery.

1.2 AIM AND OBJECTIVES

1.2.1 AIMS

This project was developed to support the requirements of the EoLB in Wales and to underpin their judgement on a future outcome measurement dataset. It aimed to develop a Wales-wide consensus on the key outcomes for inclusion in a core dataset that will measure the effectiveness of adult palliative care service delivery. In this context, an 'outcome' is defined as a 'measurable variable, such as a change in health status, quality of life or a symptom, as it is affected by a person's illness or a palliative care intervention'. The study thus focused on 'what' needs to be measured rather than 'how' to measure it (i.e., which outcome measurement tools to use).

The focus of the project was on adult palliative care, with an emphasis on specialist palliative care services.

1.2.2 OBJECTIVES

The specific objectives of the project were to:

- Demonstrate consensus on the need for a core outcome set which captures impact.
- Achieve consensus on the domains of importance.
- Consider the timing of the outcome measurement.
- Identify the next steps for consideration by the EoLB in undertaking a gap analysis of existing tools against the agreed outcome set.

Once these key achievements were in place, a further objective was to identify key future tasks (phases) for the EoLB to consider, including discussion of (1) sustainable approaches to how data will be captured, stored and reported; (2) the frequency of reporting; (3) the formats which will inform future service development and delivery; (4) the extent to which different services will engage (e.g. report all domains always, or some always) and (5) a plan for roll out.

2 METHODS AND RESULTS

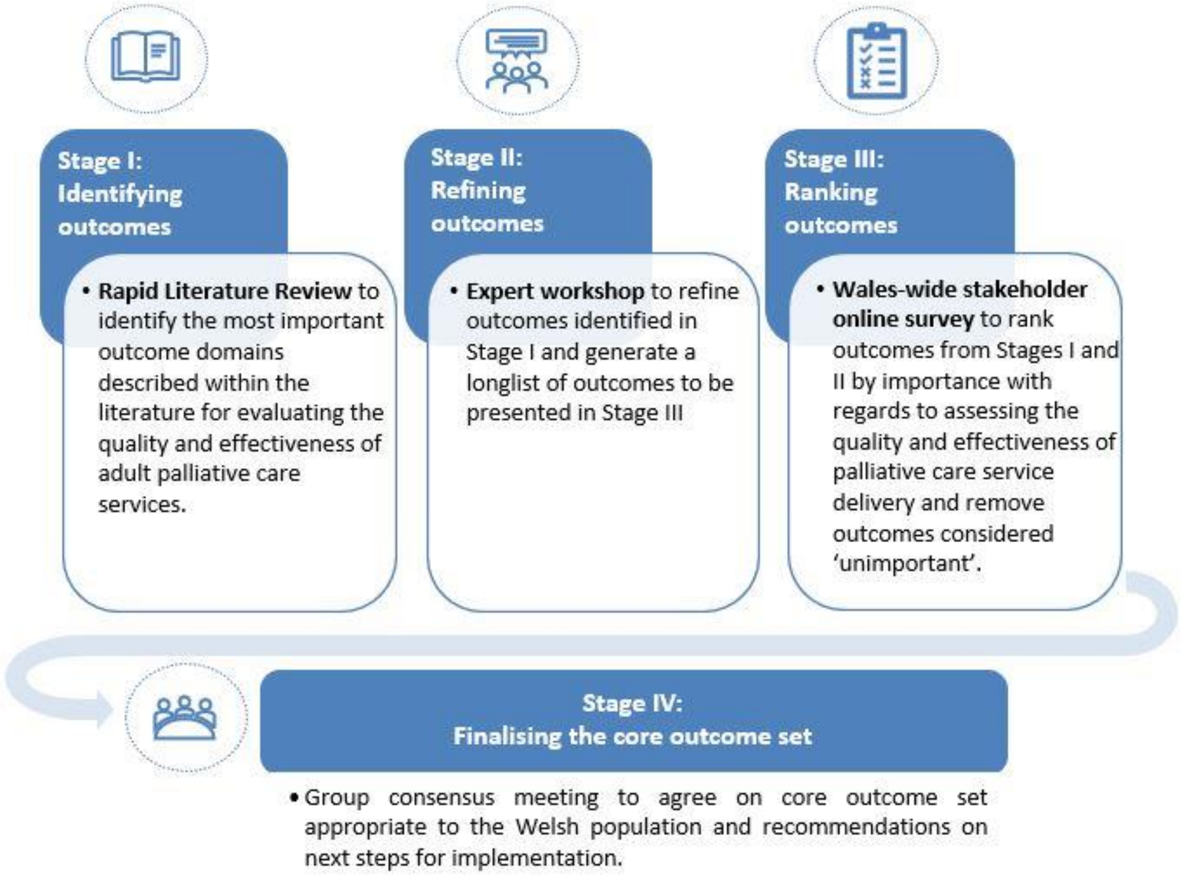
2.1 OVERARCHING STUDY DESIGN: FOUR-STAGE STUDY

The study consisted of a multi-stage (four stage) approach to produce a transparent consensus process across a range of stakeholders, consistent with approaches used previously to identify domains and measures of importance to palliative care practice and research [5, 6]. Although not intended to be a detailed COS, this process was in line with the approach recommended by the Core Outcome Measures in Effectiveness Trials (COMET) initiative [10].

The stages of the study were as follows and are represented in Figure 1:

1. Stage I: Rapid Review of existing literature – a rapid review was conducted to identify outcomes already used in the UK and internationally to measure palliative care service quality and impact.
2. Stage II: Expert consensus workshop – an expert workshop, conducted using modified Nominal Group Technique (NGT) [11, 12], to review the longlist of concepts identified in Stage I and refine it by removing those concepts which did not meet the definition for an effectiveness outcome, remove duplicate outcomes and consider any gaps; discuss what might trigger measurement/timing; and subsequently confirm the longlist of outcomes to be considered in Stage III.
3. Stage III: All Wales Ranking Survey – the longlist generated from Stages I and II was reviewed by a broader range of stakeholders from across Wales to prioritise those outcomes felt to be most important in assessing effectiveness of palliative care interventions.
4. Stage IV: Expert group meeting – a final meeting to discuss the results from Stages II and III, consider the ranked outcome set, discuss and vote on any remaining areas of uncertainty and agree on a final COS.

Fig. 1: Study design.



- **Rapid Literature Review** to identify the most important outcome domains described within the literature for evaluating the quality and effectiveness of adult palliative care services.

- **Expert workshop** to refine outcomes identified in Stage I and generate a longlist of outcomes to be presented in Stage III

- **Wales-wide stakeholder online survey** to rank outcomes from Stages I and II by importance with regards to assessing the quality and effectiveness of palliative care service delivery and remove outcomes considered 'unimportant'.

- Group consensus meeting to agree on core outcome set appropriate to the Welsh population and recommendations on next steps for implementation.

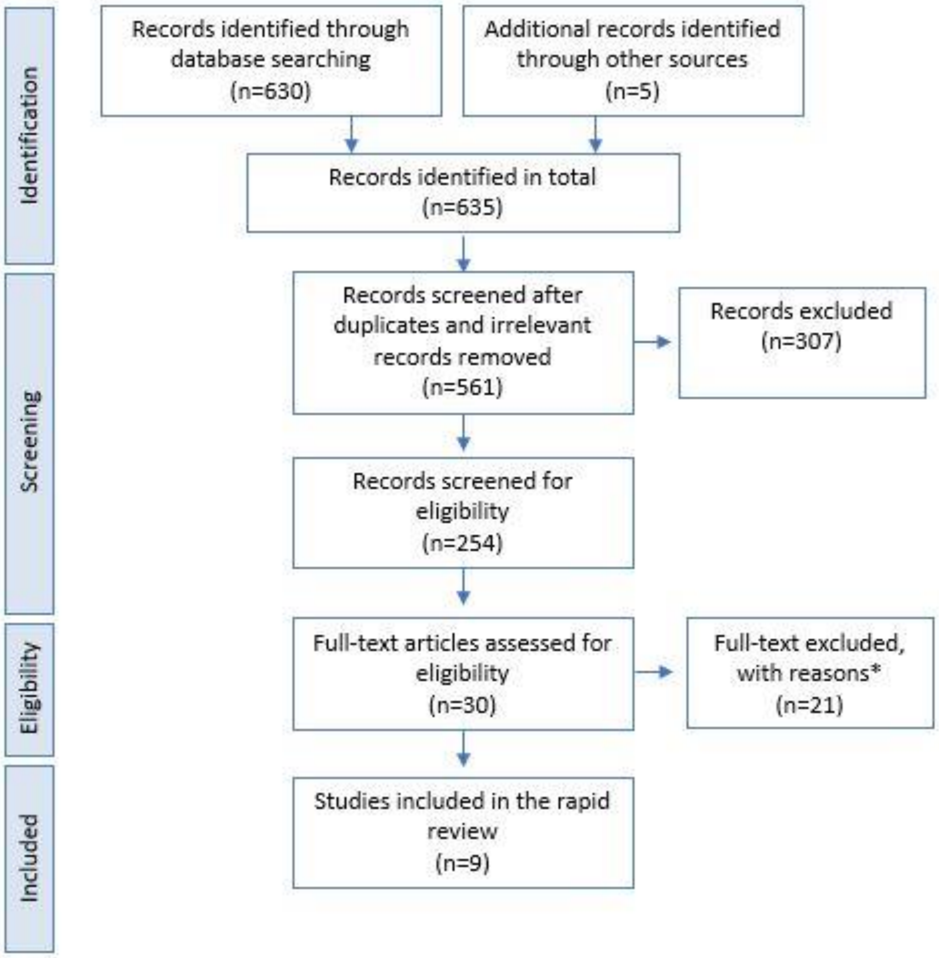
The study was granted ethical approval from the School of Medicine Research Ethics Committee (SoMREC) at Cardiff University (approval reference: SoMREC 21/79).

2.2 STAGE I: RAPID REVIEW

The initial stage of this project consisted of a rapid review of the literature to identify which domains and outcomes have been prioritized in other national and international initiatives for capturing palliative care service quality and impact, following modified systematic methodology. This rapid review was undertaken in collaboration with the Wales Cancer Research Centre (WCRC)'s Palliative Care Evidence Review Service (PaCERS) at Cardiff University and adopted its published methodological approach [13].

The literature search was restricted to articles published between January 2011 and February 2021 that addressed and reported on outcomes used to assess the quality, efficiency, and effectiveness of palliative care service delivery in adults, considering studies set in high-income OECD countries only to maintain comparability of healthcare systems. Nine studies were identified as eligible to be included in the review and a total of 62 concepts related to capturing the quality of palliative care were subsequently extracted from these studies. Figure 2 summarises the rapid review process and the flow of information through its different phases.

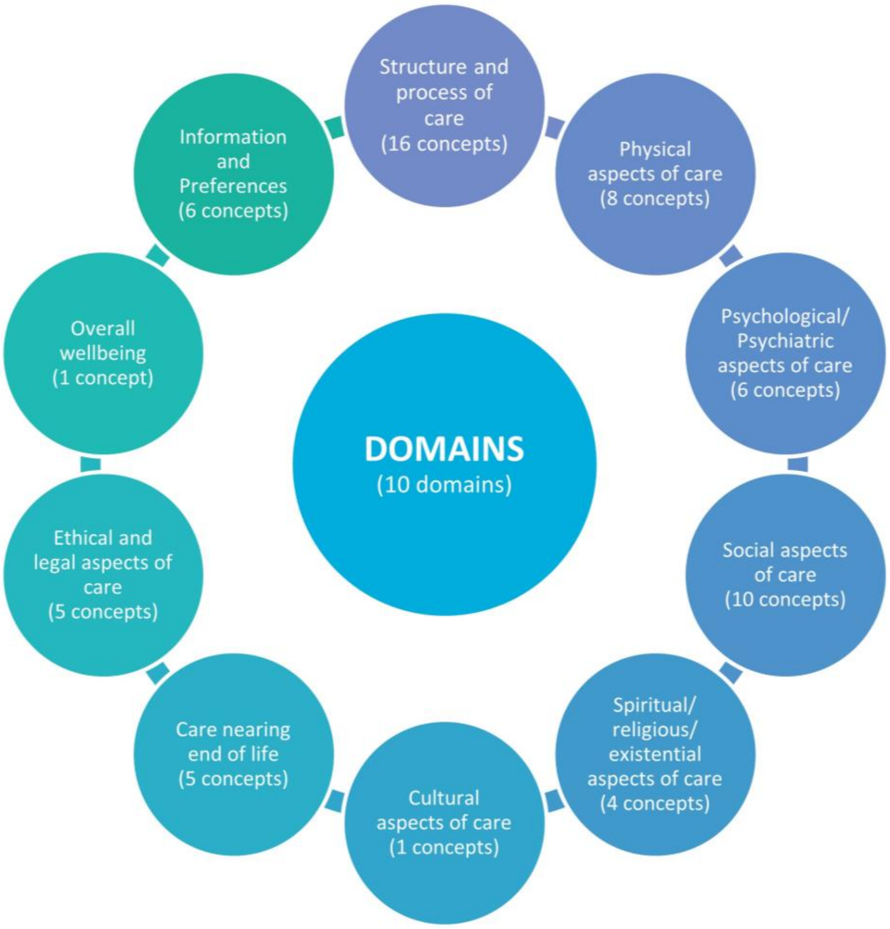
Fig. 2: Flow diagram of the rapid review process, detailing the number of abstracts screened, eligible full texts retrieved and final number of studies included in the review.



*) Primary reasons for exclusion at this stage: ‘No mention of important outcomes’ and/or ‘no assessment of important domains’.

A full list of the extracted 62 concepts will be included in the final study report. To prepare a preliminary longlist of outcomes/concepts for the next stage of the project (Stage II: Expert workshop), these 62 concepts were then mapped onto an outcomes domain framework developed based on the categories proposed by the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care [14]. These domains included: (1) Physical aspects of care; (2) Psychological aspects of care; (3) Social aspects of care; (4) Spiritual aspects of care; (5) Cultural aspects of care; (6) Care for the dying; (7) Ethical aspects of care; and (8) Structure and processes of care. The domain framework allowed outcomes to be classified within recognized domains of care to support conceptualization and facilitated the subsequent collective discussion on similarities and the ability to de-duplicate and identify gaps during the expert workshop in Stage II of the project. Importantly, two additional domains relating to (9) Overall wellbeing and (10) Information and preferences were added to the framework to accommodate a number of individual concepts thought not to fit within one of the pre-specified care domains. Figure 3 shows the mapping of the 62 outcomes across the 10 domains.

Fig. 3: Mapping of 62 concepts identified in Stage I (Rapid review) onto 10 core domains.



Full details on the rapid review [15] undertaken for this initial stage of this project will be included in the final study report. The rapid review as such can also be found here.

2.3 STAGE II: EXPERT MEETING

Following the identification of concepts from the literature, an expert consensus workshop was convened to consider the rapid review evidence identified in Stage I. Stakeholder representatives were identified via the EoLB (part of the NHS Wales Collaborative) and the Palliative Care Implementation Group in Wales, aiming to include multi-professional clinicians, policy makers, service management, and public and patient representatives. As a requirement of the ethical approval obtained for the study from the School of Medicine's Ethics Committee (SoMREC) at Cardiff University, it was the EoLB that initially approached stakeholder representatives with a meeting invitation on behalf of the research team, asking for consent for the team to contact participants about their involvement in the workshop.

The aim of the expert consensus workshop was to review the long list of concepts identified in Stage I and refine the long list by:

- removing those concepts which did not meet the definition for an effectiveness outcome (i.e., removing concepts that could not be considered a 'measurable variable, such as a change in health status, quality of life or a symptom, as it is affected by a person's illness or a palliative care intervention')
- removing duplicate outcomes
- considering any gaps in the longlist generated in Stage I
- considering what might represent a trigger for the timing of measurement

2.3.1 WORKSHOP DELIVERY

A 2-hour workshop was conducted virtually via ZOOM in March 2022, with a modified Nominal Group Technique (NGT) [11, 12] employed to deliver the workshop. This expert meeting was attended by a total of N=13 professionals with experience of providing palliative care to patients or working within/with palliative care services in Wales: Eight attendees were healthcare professionals while three worked in a non-clinical managerial role in a palliative care setting and two represented a relevant third sector organisation. A full list of workshop participants will be included in the full academic report.

Ahead of the workshop, participants were sent information on the project's purpose alongside a detailed list of the domains and concepts identified in the rapid review (Stage I). All outcomes were accompanied with a description, drawn from the definitions provided in the studies included in the rapid review, the National Cancer Institute's PRO-CTCAE outcome list, ICD-11, WHO, or NICE. To optimize the available time for the workshop, and facilitate the virtual delivery, participants were invited to reflect on all the concepts ahead of the meeting, focusing on considering whether the listed concepts met the definition of an ‘outcome’ based on how they were described, whether some concepts might be process-related instead, whether some concepts could be de-duplicated/combined, and whether any outcomes were missing. In addition, participants were encouraged to consider *when* specific outcomes should best be captured.

At the convened virtual workshop, following a short presentation to recap on the aims of the workshop and the key questions, virtual breakout rooms were created of 4-5 participants per group (diversified by geography, role, and experience) with a facilitator and scribing mechanism. Individuals were encouraged to discuss their views on the included concepts in each breakout room group, with the facilitator using a crib sheet with question prompts to keep the discussions on track and agreeing on a synopsis of the discussion within each group for each domain. Once all groups returned to the main group, the facilitators of each group provided a summary of the individual group discussions, with the main facilitator of the workshop gathering the information and summarising the obtained feedback for the whole group, agreeing suggested refinements to the wording of the concepts, deduplication/combination of concepts, removal of concepts and addition of missing concepts.

2.3.2 WORKSHOP RESULTS

The described process resulted in agreement to remove a total of 39 concepts from the longlist of concepts initially identified in Stage I (rapid review). The majority of these concepts (n=32) were removed due to being confirmed as process-related performance indicators rather than meeting the definition of an ‘effectiveness outcome’. This primarily related to concepts in the domains of ‘Process and structure of care’ (n=16), ‘Ethical and legal aspects of care’ (n=5) and ‘Information and preferences’ (n=6), with the former two domains being removed entirely from the framework at this stage and the latter being reduced to include just one single global outcome (‘Information and communication needs’) as the expert group appreciated how great of an impact communication and information can have on all other domains.

For concepts in the ‘Care nearing end of life’ domain, it was agreed that ‘end of life’ is more about a particular time in a person’s illness rather than a specific area of care that needs separate outcome measures. As all concepts related to symptom control in this domain were considered by the group as already captured in the physical and psychosocial care domains, the ‘Care nearing end of life’ domain and all the concepts it included (n=5) were removed from the longlist.

Across the remaining domains, deduplication and combination of similar outcomes, as well addition of outcomes deemed missing, resulted in further changes to the longlist of outcomes to be put forward for consideration in the next stage (Stage III: stakeholder survey). Most importantly, in the 'Physical aspects of care' domain, it was agreed to include specific symptoms rather than the initially longlisted broader composite concepts, resulting in the addition of a total of eight outcomes flagged as previously missing. In the 'Psychological/psychiatric aspects of care' domain, the expert group agreed to combine several broader concepts into one composite measure of 'Psychological needs and distress' while also adding some specific outcomes such as 'Anxiety' and 'Agitation'. For the 'Social aspects of care' domain, the expert group identified 'Family wellbeing' and 'Family carer burden' as the two most important outcomes to focus on as they were felt to capture most of the aspects described by the other concepts. Due to significant perceived overlap between the domains/concepts, the 'Spiritual/religious/existential aspects of care' and 'Cultural aspects of care' domains were combined and the concepts reduced to one composite outcome described as 'Beliefs and values' and one described as 'Feeling at peace'.

Overall, the refinements to the longlist of proposed outcomes based on the obtained expert feedback resulted in a list of 23 outcomes across 6 domains to be put forward for further consideration in the subsequent stakeholder survey. Table 2 details these outcomes, including short descriptions of the main points addressed during the group discussions. A more detailed summary of the amendments to the outcome list will be included in the final study report.

Importantly, when discussing and confirming that the concepts in the 'Process and structure of care' domains are all process-related and thus not outcomes as per the pre-defined definition, it was agreed that 'Phase of illness' is a crucial concept – not to be included as an outcome measure *per se* but important to capture alongside the to-be-identified core outcome set to determine anchor points for *when* outcomes should be measured.

Table 2: Longlist of 23 outcomes, across 6 domains, after removal of process-related concepts, deduplication/combination of similar outcomes and addition of missing outcomes in response to expert feedback obtained during the March 2022 expert workshop (N=13)

DOMAIN*	**OUTCOMES**	
Physical aspects of care	Pain	The descriptions for 'Pain' and 'Breathlessness' were amended for the concepts to represent outcomes. The previous composite measures for physical symptoms ('Screening for physical symptoms', 'General physical symptoms' and 'Physical
	Breathlessness	
	Fatigue	
	Nausea	
	Vomiting	
	Dry mouth	

	Sore mouth	symptom improvement’) were replaced with separate outcomes for specific symptoms. ‘Nausea and vomiting’ was separated into two outcomes. Several outcomes deemed missing were added: ‘Dry mouth’, ‘Sore mouth’, ‘Constipation’, ‘Loss of appetite’, ‘Performance status’, ‘Activities of Daily Living – Basic’ and ‘Activities of Daily Living – Instrumental’.
	Constipation	
	Loss of appetite	
	Performance status	
	Activities of Daily Living (Basic)	
	Activities of Daily Living (Instrumental)	
Psychological/ psychiatric aspects of care	Psychological needs and distress	It was agreed to propose inclusion of a composite measure (‘Psychological needs and distress’) alongside specific outcomes such as ‘Depression’. ‘Anxiety’ and ‘Agitation’ were deemed missing and thus added. 'Cognitive dysfunction’ was amended to ‘Cognitive function’.
	Depression	
	Anxiety	
	Agitation	
	Cognitive function	
Social aspects of care	Family wellbeing	‘Family wellbeing’ and ‘Family carer burden’ were considered to capture most of the concepts in this domain. ‘Social care’ was removed as a process-related concept. The challenging nature of the term ‘family’ was flagged, resulting in the outcome descriptions using the phrasing ‘those close to the patient’.
	Family carer burden	
Spiritual and cultural aspects of care	Beliefs and values	It was agreed to have one composite measure (‘Beliefs and values’) that captures religious, spiritual, existential beliefs and values, rather than capturing those in the form of separate outcome measures. The ‘Cultural aspects of care’ domain could thus be removed as a separate domain. ‘Feeling at peace’ was retained as an outcome that may resonate with patients.
	Feeling at peace	
Overall wellbeing	Quality of life	Difficult-to-describe concept and possibly captured within other domains. Agreed to retain for consideration in the stakeholder survey.
Information and preferences	Information and communication needs	All concepts previously included in this domain were deemed process-related. However, as communication and information impacts on all other domains, it was agreed to include a single global information and communication-related outcome measure for consideration in the stakeholder survey.
Total: 23 outcomes across 6 domains		

*Importantly, all outcomes in the ‘Process and structure of care’ domain were confirmed as process-related and thus removed. Similarly, most outcomes in the ‘Information and preferences’ and the ‘Ethical and legal aspects of care’ were considered process concepts and thus removed. For the ‘Care nearing end of life’ domain, it was agreed that ‘end of life’ is more about a particular time in a person’s illness rather than a particular area of care that needs separate outcome measures. All aspects of symptom control were deemed already captured in the physical and psychosocial care domains. All other concepts were seen as process measures captured elsewhere. The number of domains thus reduced to six while the number of outcomes reduced to 23.

2.4 STAGE III: STAKEHOLDER ONLINE SURVEY

Following the expert workshop in Stage II, the longlist of outcomes identified in Stages I and II was used to populate an online survey (Stage III) to be completed by the wider palliative care stakeholder community in Wales. The aim of Stage III was to obtain rankings of how important stakeholders from a wide range of different stakeholder groups across Wales considered each outcome to be and to gain as many relevant viewpoints as possible.

2.4.1 RECRUITMENT AND DATA COLLECTION

The survey was aimed at adult (age 18>) stakeholder representatives with either professional or personal experience of providing/receiving adult palliative care services (or supporting somebody who has received palliative care services) or working with/within palliative care services in Wales: Multi-professional clinicians, policy makers, service management, and public and patient representatives. The EoLB for Wales facilitated recruitment among professionals in the palliative care sector by identifying and reaching out to potential participants in healthcare, health policy and relevant third sector organisations with an invitation email on behalf of the study team, encouraging recipients to complete the survey and assist with the promotion of the survey among colleagues, collaborators and patients/families as appropriate (e.g. via social media channels (Facebook, Twitter), newsletters, website etc.).

The survey was generated using Online Survey UK and consisted of one round. Participants were asked to rate for each outcome how important they felt it was to include the outcome in a core outcome set on a scale from 1 (*not important at all*) to 9 (*critically important*). Participants also had the option to respond with ‘Unable to rate’ if they felt unsure or unable to provide a rating and were given the opportunity to add comments on their ratings via free text boxes provided in the survey.

2.4.2 DATA ANALYSIS

For each outcome, the obtained ratings on the 9-point scale from 1 *(not important at all)* to 9 *(critically important)* were summarised into three categories:

- Ratings between 1-3 were categorised as ‘not important’
- Ratings between 4-6 were categorised as ‘maybe important, maybe not’
- Ratings between 7-9 were categorised as ‘important’

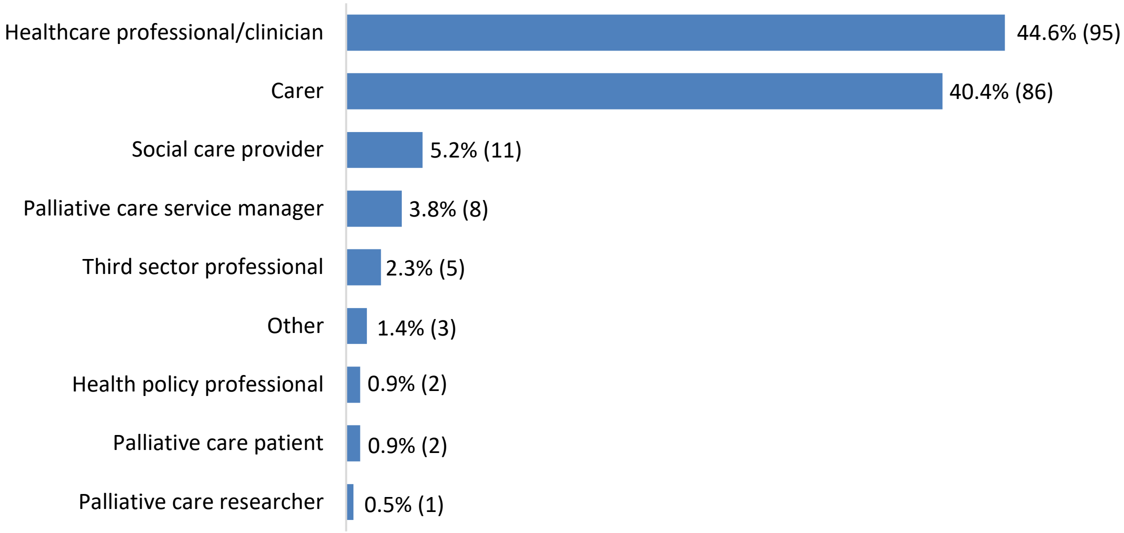
The agreed benchmark score for ‘consensus to include’ was ≥70%, based on thresholds used in comparable Core Outcome Set development studies [16,17]. Outcomes were proposed for inclusion in the final agreed domain set if 70% or more respondents rated the item as ‘important’ (receiving scores of 7-9), and 15% or fewer rated the item as ‘unimportant’ (receiving scores of 1-3). The same principle was applied to ‘consensus to exclude’, in which outcomes were proposed for exclusion should ≥70% or more rate the outcome as ‘unimportant’ (score of 1-3) and 15% or fewer rate the outcome as ‘important’ (score of 7-9). Outcomes that did not come under either of these, were to be considered as having ‘no consensus’.

If applicable, comments provided alongside stakeholder ratings in the form of free text responses were inspected and, if appropriate, summarised to be included in the subsequent final discussion and agreement on the final outcome set in the Stage IV expert meeting.

2.4.3 SURVEY SAMPLE DESCRIPTION

The Wales-wide online stakeholder survey was open from 6th May to 27thMay 2022. During this time, a total of 213 stakeholders completed the survey, primarily healthcare professionals involved in providing palliative care (44.6%; n=95) and informal caregivers with experience of supporting a family member or friend receiving palliative care (40.4%; n=85). A small number of non-clinical professionals with experience of working with or within palliative care services responded as well, i.e. social care providers (5.2%; n=11), non-clinical staff working in managerial roles in palliative care settings (3.3%; n=7), relevant third sector professionals (2.3%; n=5), health policy professionals (0.9%; n=2) and a palliative care researcher (0.5%; n=1). In addition, two patients completed the survey (0.9%; n=2). Of those who indicated that their primary experience with palliative care services was in a professional capacity – either clinically as a healthcare provider or non-clinically as e.g. a service manager, social care provider or health policy expert – 13.1 % also reported having personal experience of caring for a person close to them receiving palliative care. Figure 4 summarises the different stakeholder groups that participated in the online survey.

Fig. 4: Summary of participating stakeholder groups in the Stage III survey.



Across all participating stakeholders, the majority of of respondents were female (89.7%; n=191). A small number of respondents self-identified as being from minoritised ethnic communities (2.8%; n=6), as detailed in Table 3 below.

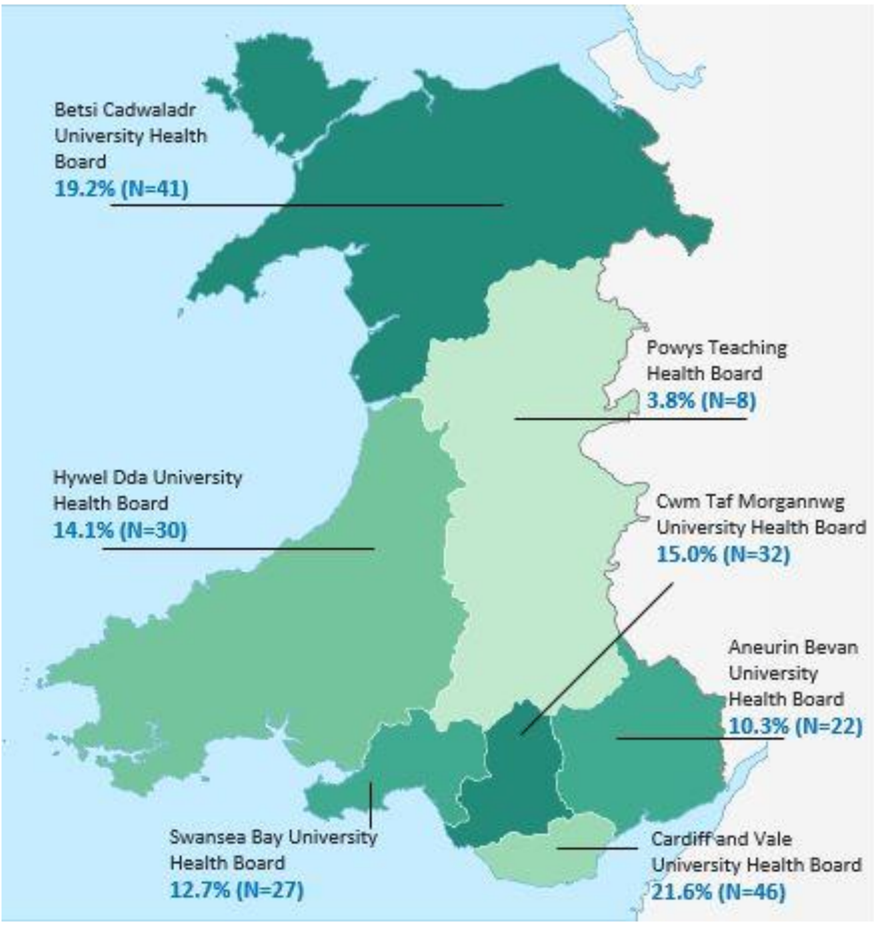
Table 3: Demographic characteristics of participanting palliative care stakeholders.

	n	%
Age (years)		
18-24	1	.5%
25-34	22	10.3%
35-44	50	23.5%
45-54	62	29.1%
55-64	60	28.2%
65-74	15	7.0%
75+	2	0.9%
no response	1	.5%
Gender identity		
Female	191	89.7%
Male	18	8.5%
Prefer not to say	3	1.4%
no response	1	.5%
Ethnic background		
Non-BAME	202	94.8%
BAME	6	2.8%
Prefer not to say	4	1.9%
no response	1	0.5%
Primary experience of palliative care services in Wales as a…		
Healthcare professional	95	44.6%

Carer	86	40.4%
Social care provider	11	5.2%
Palliative care service manager	8	3.8%
Third sector professional	5	2.3%
Other	3	1.4%
Patient	2	0.9%
Health policy professional	2	0.9%
Palliative care researcher	1	0.5%
Area (based on local authority)		
Blaenau Gwent	8	3.8%
Bridgend	10	4.7%
Caerphilly	5	2.3%
Cardiff	34	16.0%
Carmarthenshire	12	5.6%
Ceredigion	6	2.8%
Conwy	12	5.6%
Denbighshire	3	1.4%
Flintshire	10	4.7%
Gwynedd	9	4.2%
Isle of Anglesey	4	1.9%
Merthyr Tydfil	3	1.4%
Monmouthshire	3	1.4%
Neath Port Talbot	9	4.2%
Newport	1	0.5%
Pembrokeshire	12	5.6%
Powys	8	3.8%
Rhondda Cynon Taf	19	8.9%
Swansea	18	8.5%
Torfaen	5	2.3%
Vale of Glamorgan	12	5.6%
Wrexham	3	1.4%
Other	4	1.9%
no response	3	1.4%
Area (based on NHS Health board*)		
Aneurin Bevan University Health Board	22	10.3%
Betsi Cadwaladr University Health Board	41	19.2%
Cardiff and Vale University Health Board	46	21.6%
Cwm Taf Morgannwg University Health Board	32	15.0%
Hywel Dda University Health Board	30	14.1%
Powys Teaching Health Board	8	3.8%
Swansea Bay University Health Board	27	12.7%
Other	4	1.9%
no response	3	1.4%

Figure 5 summaries the percentage of stakeholder survey responses from the different health board areas, demonstrating that responses were obtained from all health board areas across Wales.

Fig. 5: Response rates across stakeholder groups for each of the 7 NHS Health Boards in Wales*



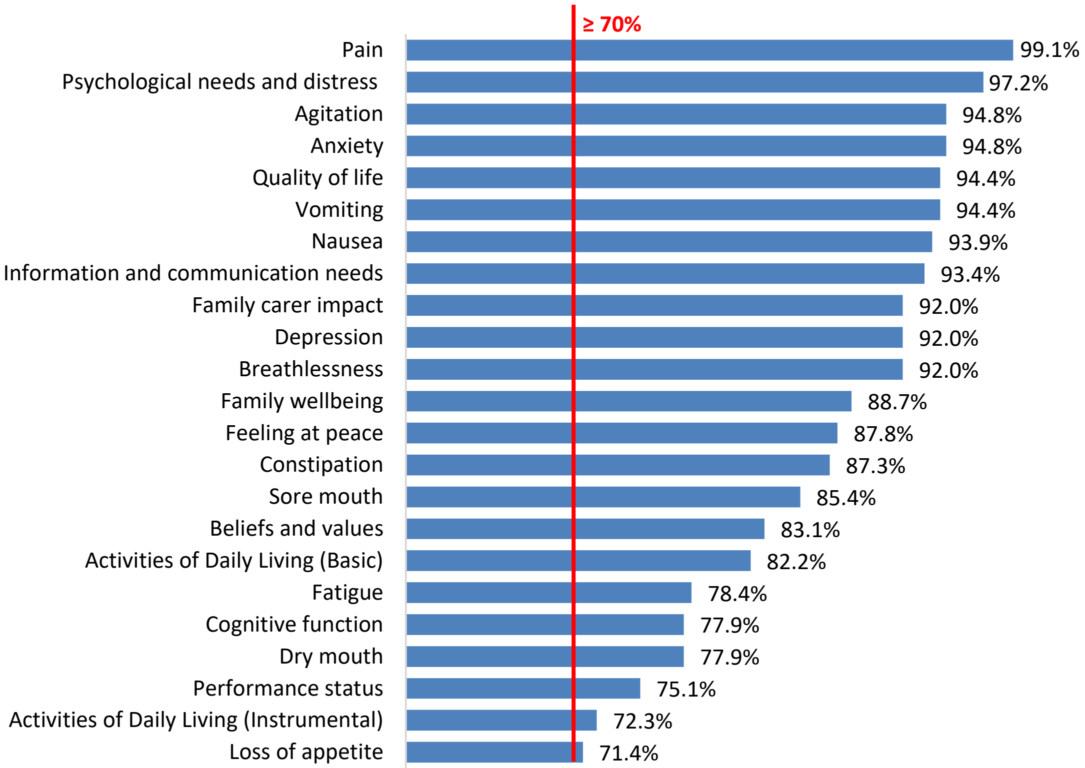
*) Map adapted from Wikimedia Commons. 3.3 % (n=7) of respondents had selected either 'Other area outside of Wales' or provided no/vague information on the area they live in.

Among the participating healthcare providers (n=95), the majority were nurses (36.8%; n=35), doctors (28.4%; n=27) and allied health professionals (AHPs; 10.5%; n=10). Those who provided details on their main area of practice/speciality in the form of free text responses, 42.1% (n=40) described working in palliative medicine/end of life care/hospice care while smaller percentages indicated that they worked in district nursing (7.4%; n=7), oncology (6.3%; n=6), community nursing (3.2%; n=3), general medicine (3.2%; n=3), Accident & Emergency (2.1%; n=2) or in a pharmacy (2.1%; n=2). Most participating healthcare providers' primary work setting was in community care (44.9%; N=40) and/or secondary care settings (40.4%; n=36).

2.4.4 OUTCOME RATINGS AND CONSENSUS THRESHOLD

All 23 outcomes were rated as ‘important’ (i.e. rating scores between 7 and 9 on the 9-point scale) by the majority of respondents, with percentages of stakeholders considering an outcome as important to include in the core outcome set consistently above 70% for all outcomes. Ratings as ‘unimportant’ (i.e. rating scores between 1 and 3 on the 9-point scale), on the other hand, were very low and ranged between 0.0% and 3.3% for all outcomes. Therefore, all proposed outcomes rated in the survey met the criteria for ‘consensus to include’ (i.e. ≥ 70% stakeholders rated outcome as ‘important’ and ≤ 15% rated as ‘unimportant’). A full table detailing all ratings for each outcome will be included in the final study report. Figure 6 below focuses on showing ratings as ‘important’ only for all outcomes, to due the very low percentages for ratings other than ‘important’.

Fig. 6: Percentage of stakeholders rating an outcome as ‘important’ to include in the core outcome set (i.e. rating scores 7-9), in descending order of perceived importance.



--- marks the consensus criterion of 70%: Consensus to include an outcome in the final outcome set was achieved if ≥ 70% of respondents rated an outcome as ‘important’ and ≤ 15% of respondents rated the outcome as ‘not important’ (‘not important’ ratings not shown in this chart due very low percentages).

2.4.5 SURVEY FREE TEXT RESPONSES

For each outcome, a small percentage of respondents provided free text comments along with their outcome ratings, usually pertaining to why they felt a particular outcome was important to include in the outcome set. A small number of individual comments, however, flagged potential issues with some of the outcomes. Due to the study including only a one-round survey with no option for further feedback from the wider stakeholder community, the study team deemed it important to include the raised questions in the final consensus meeting, with the most important being:

- **‘Physical aspects of care’ domain**: Should ‘Nausea’ and ‘Vomiting’ be considered on a spectrum rather than two separate outcomes? Should ‘Dry mouth’ and ‘Sore mouth’ be combined? Should ‘Performance status’, ‘Activities of Daily Living (Basic)’ and ‘Activities of Daily Living (Instrumental)’ remain independent outcomes or is there overlap?
- **‘Psychological/psychiatric aspects of care’ domain**: Should the term ‘distress’ be changed to ‘mental wellbeing’? Should ‘Anxiety’ and ‘Depression’ be combined?
- ‘**Social aspects of care’ domain**: Is the use of the term ‘family’ appropriate?
- **‘Cultural aspects of care’ domain**: Is ‘Beliefs and values’ indeed an outcome as per definition?

2.5 STAGE IV: FINAL MEETING

2.5.1 MEETING DELIVERY

The fourth and final stage of this project consisted of a small Expert Group meeting convened virtually via Microsoft TEAMS in early July 2022 to consider the ranked outcome set, discuss and vote on any remaining areas of uncertainty and confirm the final core outcome set. The meeting was attended by five professionals with experience of working with/within palliative care services in Wales as healthcare professionals/clinicians or in non-clinical managerial roles. In addition, one attendee represented a relevant third sector organisation (Compassionate Cymru) and one represented the Wales Value in Health Centre (WViHC) (a full list of participants will be included in the full study report). An additional participant with experience of managing a third sector palliative care setting was unable to join the group meeting and instead attended a meeting with the study team the previous day. Their opinions and votes were documented and a member of the study team voted on their behalf during the final meeting.

Similarly to the Stage II Expert meeting, it was again the EoLB – part of the NHS Wales Collaborative - and the Palliative Care Implementation Group in Wales who identified and initially approached stakeholders about participating in this meeting. Once potential participants expressed an interest in taking part to the EoLB, the study team contacted them with further information about the meeting and its purpose. Prior to the meeting, all participants were sent a summary of the analysis of the Stage III stakeholder survey. During the meeting, all outcomes prioritised for inclusion in the core outcome set based on the survey results were discussed taking comments from the survey's free text responses into account. Any areas of uncertainty were discussed and voted upon. Voting was conducted via Online Survey UK. For all domains, the initial question to be voted on was whether or not participants agreed with the grouping of the outcomes in a given domain, with additional questions informed by stakeholder survey comments added, if needed. Once all outcomes in a specific domain had been discussed sufficiently, participants were provided with an online link to the set of questions to be voted on for this domain and were then able to cast their vote anonymously, with consensus assumed if ≥ 70% of participants agreed in their votes.

The results of these final votes (and subsequent agreed-upon amendments to the outcome list if applicable) were considered formal acceptance of the final core outcome set.

Participants were then invited to discuss the next steps for consideration by the EoLB towards implementation of the core outcome set, including consideration of the suitability of existing outcome measurement toolkits (e.g. OACC, PCOC) for capturing the core outcomes identified in this project in preparation for a detailed gap analysis in a dedicated future piece of work.

The entire expert group meeting was digitally recorded and subsequently transcribed in-house by a member of the study team and summarised to document the final decisions and recommendations made during this meeting. The obtained votes were exported from the survey platform for documentation purposes as well.

2.5.2 FINAL CHANGES TO OUTCOME SET AND FORMAL RATIFICATION

After clarifying that the default approach would be to heed with the results of the survey and include all 23 outcomes, clustered into the 6 domains as they were, as they had all met the 'consensus to include' threshold of being rated 'important' by ≥ 70% of stakeholders, attendees were asked to vote on a number of questions. Similar to the stakeholder survey, consensus was assumed if ≥ 70% of participants agreed. The initial vote related to whether or not the two outcomes very close to the 'consensus to include' threshold ('Activities of Daily Living (Instrumental)' and 'Loss of appetite'; rated ‘important’ by 72.3% and 71.4% of stakeholders, respectively) should indeed be included in the final core outcome set.

Subsequent voting addressed the separate domains, asking to confirm whether participants agreed with the grouping of the outcomes and, where necessary based on specific feedback comments and questions from survey participants, asking for a decision on e.g. whether or not certain outcomes should be combined after all or their wording amended.

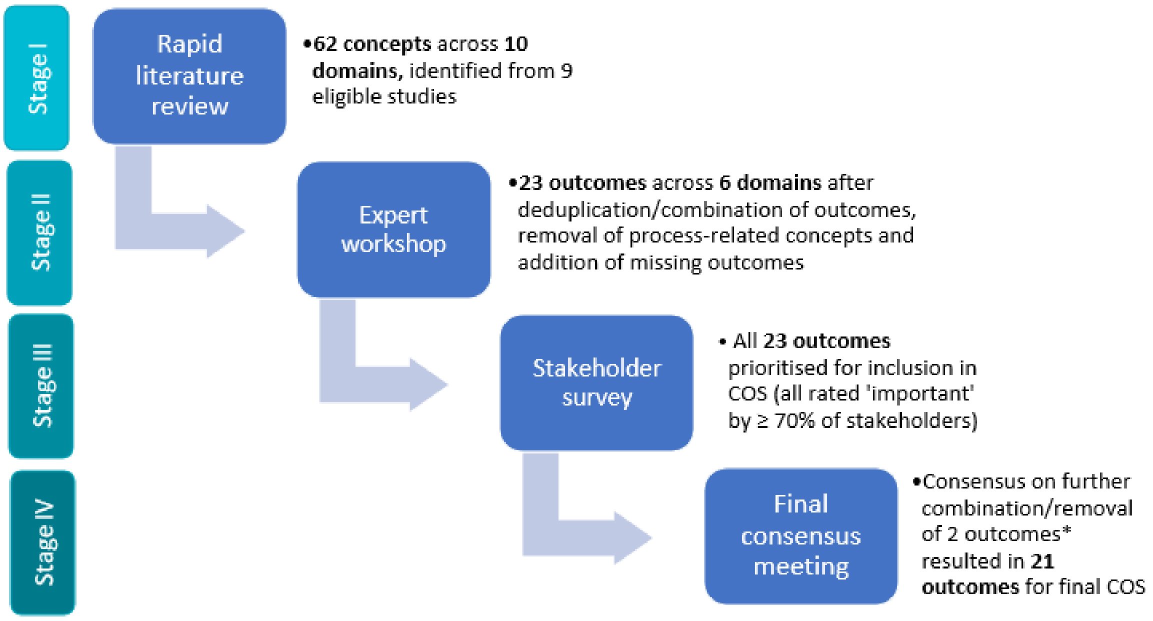
Table 4 details the questions put to a vote to formally finalise the core outcome set. While eight participants provided votes on the first question (‘Do you agree that ‘Activities of Daily Living (Instrumental)’ should be included?), subsequently one participant asked not to continue voting as they felt they didn’t have the necessary clinical experience. Therefore, all subsequent votes were based on seven participants.

Table 4: Votes obtained during the final expert meeting, with votes that resulted in amendments to the final core outcomes set marked with ***.

Voting question	Yes	No
Inclusion of outcomes close to 70% ‘consensus to include’ threshold		
Do you agree that ‘Activities of Daily Living – Instrumental’ should be included in the core outcome set?	87.5% (n=7)	12.5% (n=1)
Do you agree that ‘Loss of appetite’ should be included in the core outcome set?	87.5% (n=7)	12.5% (n=1)
DOMAIN: PHYSICAL ASPECTS OF CARE		
Do you agree with the grouping of these outcomes within this domain?	71.4% (n=5)	28.6% (n=2)
Do you agree that ‘nausea’ and ‘vomiting’ should remain separate?	71.4% (n=5)	28.6% (n=2)
Do you agree that ‘dry mouth’ and ‘sore mouth’ remain separate?* **	**42.9% (n=3)**	**57.1% (n=4)**
Do you agree that ‘Performance Status’ remains an independent outcome?	85.7% (n=6)	14.3% (n=1)
Do you agree that ADLs should be separated into ‘basic’ and ‘instrumental’?	85.7% (n=6)	14.3% (n=1)
DOMAIN: PSYCHOLOGICAL/PSYCHIATRIC ASPECTS OF CARE		
Do you agree with the grouping of these outcomes within this domain?	100.0% (n=7)	0.0% (n=0)
Do you think that ‘distress’ should be changed to ‘mental wellbeing’?	0.0% (n=0)	100.0% (n=7)
Do you agree that ‘anxiety’ and ‘depression’ should remain as separate outcomes?	100.0% (n=7)	0.0% (n=0)
DOMAIN: SOCIAL ASPECTS OF CARE		
Do you agree with the grouping of these outcomes within this domain?	100.0% (n=7)	0.0% (n=0)
Do you agree with the use of the word ‘family’?	100.0% (n=7)	0.0% (n=0)
DOMAIN: CULTURAL AND SPIRITUAL ASPECTS OF CARE		
Do you agree with the grouping of these outcomes within this domain?	85.7% (n=6)	14.3% (n=1)
Do you agree that ‘beliefs and values’ is an outcome?* **	**28.6% (n=2)**	**71.4% (n=5)**
DOMAIN: OVERALL WELLBEING		
Do you agree with the grouping of the outcome here?	100.0% (n=7)	0.0% (n=0)
DOMAIN: INFORMATION AND PREFERENCES		
Do you agree with the grouping of the outcome here?	100.0% (n=7)	0.0% (n=0)

Overall, participants agreed with the final outcome set as proposed based on the stakeholder survey results from Stage III, with two exceptions: While it was appreciated that ‘Dry mouth’ and ‘Sore mouth’ are two different kinds of experiences that would warrant being captured as two separate outcomes, it was agreed to combine them into one outcome described as ‘Sore and/or dry mouth’ to reduce the burden on patients during data collection. In addition, there was consensus that ‘Beliefs and values’ – while important to capture their documentation elsewhere – does not meet the definition of an ‘outcome’, thus removing this concept from the final list of outcomes. Therefore, the final core outcome set formally agreed on during the expert meeting comprised 21 outcomes across 6 domains. Figure 7 summarises the process of refinement to the outcome list across the different project stages, from the initially identified 62 concepts across 10 domains from the rapid review (Stage I) to the final list of 21 outcomes across 6 domains. Table 5 details the 21 outcomes proposed for inclusion in the final core outcome set, along with their descriptions.

Fig. 7: Refinement of concepts/outcomes and domains across study stages I-IV



*) There was consensus to combine ‘Dry mouth’’ and ‘Sore mouth’ into one outcome to reduce the burden on patients during data collection. In addition, ‘Beliefs and values’ was agreed to not meet the definition of an ‘outcome’ and was therefore not recommended for inclusion in the final core outcome set.

Table 5: Final list of 21 outcomes to be recommended for inclusion in the core outcome set for the evaluation of the effectiveness of adult palliative care services in Wales, clustered into 6 domains.

Outcome	Description
DOMAIN: PHYSICAL ASPECTS OF CARE (11 outcomes)	
01 **Pain**	A person's experience of acute or chronic pain caused by their underlying illness or its treatment.
02 **Breathlessness**	A person's experience of shortness of breath.
03 **Fatigue**	A person's experience of fatigue, tiredness, weakness or lack of energy.
04 **Nausea**	A person's experience of feeling the urge to vomit.
05 **Vomiting**	A person's experience of vomiting.
06 **Dry and/or sore mouth**	A person's experience of having a dry or parched mouth, tongue or lips and/or of having discomfort in the mouth, tongue or lips.
07 **Constipation**	A person's experience of passing small, hard faeces infrequently or with difficulty, and less often than is normal for that individual.
08 **Loss of appetite**	A person's experience of a lack of appetite, not feeling hungry, or finding food unappealing as distinct from a feeling of nausea.
09 **Performance status**	A combined assessment of a person's overall function including mobility, self-care and work.
10 **Activities of Daily Living (Basic)**	A person's daily functioning to allow self-care such as feeding, personal toileting, bathing, dressing and undressing.
11 **Activities of Daily Living (Instrumental)**	A person's ability to undertake activities which allow them to live independently and participate in the community.
DOMAIN: PSYCHOLOGICAL ASPECTS OF CARE (5 outcomes)	
12 **Psychological needs and distress**	A combined measure of a person's overall psychological distress
13 **Depression**	A person's experience of low mood, sadness, emptiness, hopelessness, or dejection.
14 **Anxiety**	A person's experience of feeling anxious or apprehensive or anticipating future dread which might be accompanied by restlessness, and tension.
15 **Agitation**	A person's experience of a state of restlessness associated with unpleasant feelings of irritability and tension.
16 **Cognitive function**	An overall assessment of a person's cognitive function.
DOMAIN: SOCIAL ASPECTS OF CARE (2 outcomes)	
17 **Family wellbeing**	The overall mental, physical and social wellbeing of those close to the patient and regularly involved in their care.
18 **Family carer impact (**across physical and psychosocial domains)	The level of multifaceted impact which caring for the patient has on the daily lives of those close to them.
DOMAIN: SPIRITUAL ASPECTS OF CARE (1 outcome)	
19 **Feeling at peace**	A person's experience of feeling calm and contented and not at conflict within themselves or with others.

DOMAIN: OVERALL WELLBEING (1 outcome)	
20 **Quality of life**	A person’s assessment of how their physical, emotional, social or other forms of well-being are affected by their illness or its treatment.
DOMAIN: INFORMATION AND PREFERENCES (1 outcomes)	
21 **Information and communication needs**	An overall measure of the extent to which the person has received all the information they need in relation to their illness and care.

2.5.3 DISCUSSION OF NEXT STEPS TOWARDS IMPLEMENTATION

Following the formal ratification of the final core outcome set, attendees were invited to share their views on the steps needed to implement the core outcome set at pace, focussing on two main questions:

1. What existing outcome toolkits might be appropriate?
2. How will this data be captured – in a way that ensures the data are being viewed as aligning with other measures of quality (e.g. service efficiency, patient experience)?

It was suggested that the first step – the identification of one or more existing outcome measurement toolkits suitable for capturing the identified outcomes – could be achieved by discussions facilitated by the new Programme Board for Palliative and End of Life Care with key stakeholders to identify a list of candidate measures/toolkits for further consideration. A formal mapping exercise to map the outcomes over onto these existing toolkit(s) and identify any gaps can then be undertaken facilitated by the Marie Curie Research Centre and the Wales Value in Health Centre (WViHC).

The second step – data gathering, analysis and presentation – will require further collaboration between the new Programme Board and Digital Health and Care Wales (DHCW) to establish where the data will be routinely captured and where it is going to be available, both locally for palliative care teams to support service planning and nationally for policy and strategy judgements. In this context, it is important to ensure that the effectiveness core outcome set does not remain a separate data set but is presented alongside efficiency, safety and patient experience data. The project was therefore seen as feeding directly into the WViHC’s ongoing work within the NHS Wales Collaborative on the development of dashboards to describe all the different dimensions of quality of care in one place and to enable services to access their own local service reports as well as national data. With regards to the practicalities associated with implementing the core outcome set, the importance of taking advantage of training resources and infrastructure that already exist for other outcome measurement tools was highlighted, along with the importance of having reporting infrastructure in place (ideally prior to implementation for early feedback) that makes it easy for services to extract and report on their local data.

Ensuring that patients and families understand the purpose of why this information is collected and making the obtained data easily accessible to them was also emphasised as important. The option of patient apps that would allow patients to enter and access their own data was mentioned in this context. It was also suggested that Compassionate Cymru might be well-placed to help shape the messaging around the importance of outcome measurement as part of the public discussion of palliative and end-of-life care.

While achieving an all-Wales consensus on what outcomes are important to measure as part of a core outcome set is an essential step towards being able to benchmark due to increased consistency in data collection across services, the question was raised to what extent the outcome set should be aligned with other UK nations or even other developed nations to allow for wider benchmarking and facilitate cooperation in UK-wide/international projects.

3 SUMMARY

In light of the increasing emphasis on the inclusion of more impact-focussed domains such as quality and effectiveness when it comes to care delivery assessment [3,4], the EoLB has prioritised the need to establish a standardised approach to collecting such data in Wales by, importantly, first establishing consensus on what outcomes are important to capture (i.e. ‘what’ needs to be measured) and then considering appropriate measurement toolkits (i.e. ‘how’ to measure).

This 4-stage project to develop a core outcome set for the evaluation of the effectiveness of palliative care services in Wales was developed in support of that, ensuring that the specific health and social care economy unique to Wales is reflected in an all-Wales multi-perspective consensus. The level of engagement with the exercise from across Wales - the stakeholder survey attracted more than 200 participants from across all parts of Wales (with 40% being caregivers) – attests to its perceived importance. The finalised outcome set has 21 outcomes across 6 domains.

In delivering the outcome set, the project acknowledges that rapid transition to implementation into practice is essential. Feedback during the project has emphasised the importance of a manageable dataset (which we feel the project has delivered) to aid data completion; how crucial it is to engage with the clinical community to agree on a uniform measurement toolkit for use across Wales capable of benchmarking internally and with services outside of Wales; and easy accessibility of accumulated data for local and national use. Throughout the project we have endeavoured to regularly report our aims and progress back to the End-of-Life Board and WViHC to ensure readiness for those next stages in a way that will allow sustainable and at pace implementation of a useable and accessible clinical dataset.

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