Canolfan Ymchwil Canser Cymru
Wales Cancer Research Centre

Palliative and Supportive Care Research Development

What does Future Care Planning look like within end-of-life care? A scoping review of the literature

February 2025

Clinical and Policy Implications:

The evidence base indicates that Future Care Planning (FCP) is being increasingly applied in palliative care settings worldwide and has been adopted as part of several national strategies, including in Wales and in Scotland. In Wales, the term was chosen by patient/carer advocates as a more understandable phrasing, compared with more established names such as anticipatory or advance care planning. One of the core activities is the traditionally understood advance care planning ethos; importantly it includes and incorporates patients with diminished capacity at the time of information gathering, for whom a best interest decision making approach should be followed. A clear and consistent definition of Future Care Planning would support health and social care professionals working in frailty and palliative care.

Our review identified definitions of 'Future Care Planning' in the existing literature and described what a 'Future Care Plan' is, including what end-of-life care should look like and incorporate.

Evidence provided in this review will help inform the definition within current local and national workstreams, providing better clarity on definitions with regards to end-of-life care and specific forward planning. This review will provide a much-needed assessment of future care planning, supporting health and social care professionals in practice and providing a clear definition. Our findings will inform government policy, particularly around the domains of elderly care and frailty.

Strengths & Limitations

A strength of this review is that we incorporated a range of study designs to summarize the evidence. A comprehensive search was carried out with available evidence was mapped to the topic. The search strategies are systematic, transparent and reproducible.

However, it is important to note limitations inherent in scoping review methodology, in this case, the review did not contain detailed quality assessment of included studies.

Context

Future Care Planning (FCP) is an umbrella term being increasingly applied in palliative care settings. FCP has been adopted as part of several national strategies, with NHS Wales and NHS Scotland being notable examples. In Wales, FCP as a terminology to improve end-of-life care was chosen by patient/carer advocates as a more understandable term than 'Advance Care Planning'. One of the core activities of FCP is the traditionally understood advance care planning or anticipatory care planning ethos; but importantly, FCP proactively includes and incorporates patients with diminished capacity at the time of information gathering, for whom a best interest approach should be followed. A clear and consistent definition of FCP will support health and social care professionals, particularly those working in frailty and palliative care.

The aim of this rapid scoping review is to identify all definitions of 'Future Care Planning' in the existing literature and describe what a 'Future Care Plan' should look like, and incorporate, with regards to preferences and advance planning in end-of-life care.

The findings will inform Welsh Government policy, particularly around the domains of elderly care and frailty.

Research Questions;

· Is there a definition for 'Future Care Planning' in the existing literature?

· Is there a description of what a 'Future Care Plan' should look like or incorporate with regards to end-of-life care and advance care planning?

Key Findings

Database and supplementary searches generated 199 records in total. After removing duplicates and irrelevant records, 167 articles were screened for eligibility. The iterative nature of scoping reviews allows the inclusion of different types of literature including overviews, letters and even papers with no primary data so long as the included articles are likely to contain relevant information to answer the review questions.

Figure 1 shows the flow of information through the review. We identified 77 articles for full text screening, 36 of which were conference abstracts. We were unable to assess them due to the unavailability of full text.

We identified a total of 21 articles which addressed definitions of FCP and provided a description of what a 'Future Care Plan' should look like and incorporate, with regards to end-of-life care preferences and advance care planning.

The majority of included papers (n=11) were based in the UK (Benson & Mucci 2015, Denvir et al., 2016, Denvir et al., 2014, Denvir et al., 2015, Haire et al.,2024, Hyson et al.,2024, Kinley et al.,2018, Taubert & Bounds 2022, Taubert, & Duffy 2024, Taubert et al., 2022, Taubert et al., 2023). Two studies were from the United Kingdom and Ireland (McIlfatrick et al., 2018) and the United Kingdom and the Netherlands (Rietjens et al., 2021). Four papers were based in the USA (Huber et al., 2023, Jorgenson et al.,2016, Kahana et al.,2020, Lee et al., 2023), one was based in both Canada and USA (Meyers, et al.,2016), two were based in Australia (Liang et al., 2023, Janice et al., 2023) and one was based in both India and USA (Sivakumar 2022).

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Review Methods

Search Strategy:

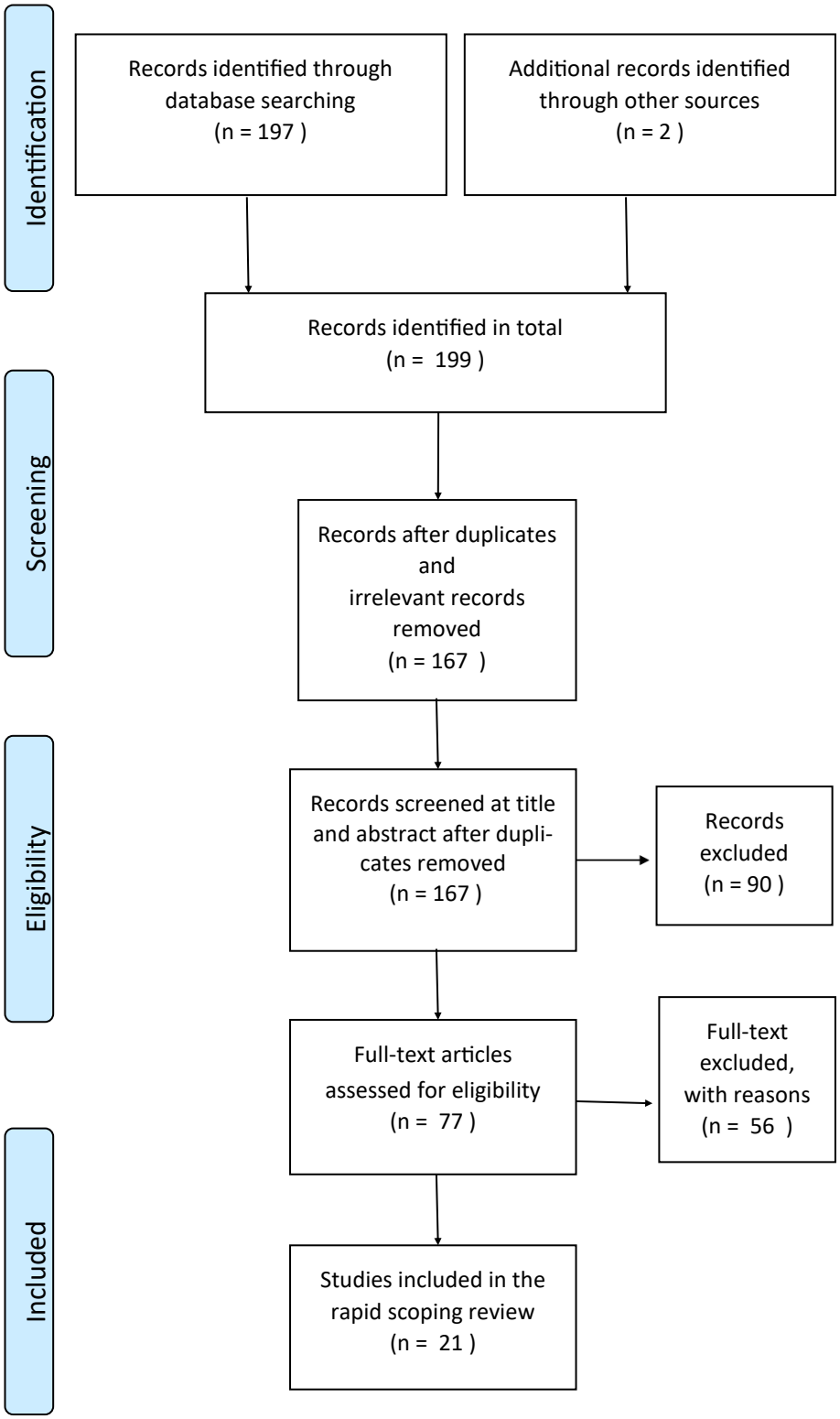
A search was conducted across a wide-ranging set of databases: Ovid Medline, including In-Process & Other Non-Indexed Citations, Ovid Embase, Scopus and Web of Science Core Collection including Science Citation Index Expanded, Social Sciences Citation Index, Arts & Humanities Citation Index, and Emerging Sources Citation Index. The preliminary search strategy was developed on Ovid Medline using both text words and medical subject headings and restricted to English language. The search strategy was modified to capture indexing systems of the other databases.(Search strategies available upon request). The databases were searched from January 1999 – 5 July 2024. Reference lists of systematic reviews were checked for relevant studies. Overall, the searches generated 167 citations after removing duplicates and irrelevant records. Figure 1 represents the flow of information through the different phases of the review.

Inclusion: All literature, including grey literature articles, that provided a definition of FCP. Related to patients living with frailty and/or palliative/life-limiting illness.

Exclusion: Articles not providing a definition, relating to children, book chapters.

Study selection/Quality Assessment/Data Extraction: Study selection was based upon review of the abstract by two independent reviewers. The full text was then assessed independently using a pre-designed eligibility form according to inclusion criteria. Data extraction was carried out by one reviewer and checked by another using a pre-specified data extraction form. Quality assessment was not undertaken due to the review type being a scoping review. Any discrepancies between the two reviewers were resolved by consensus or by recourse to a third reviewer.

Figure 1. Flow Diagram:



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Key Findings (continued)

Throughout the literature, multiple terms were used to describe components of FCP, ranging from Advance Care Planning and Health Care Directives to Treatment Escalation Plans, see Box 1.
One paper (Liang et al., 2023) for example, used the following 5 terms to describe FCP:

· Advance Care Planning (ACP)
· Advance Care Directives (ACD)
· State Administration Tribunal (SAT)
· Enduring Power of Attorney (EPA)
· Enduring Power of Guardianship (EPG)

Box 1. Terms Used to describe components of Future Care Planning

- Advance Care Directive (ACD)
- Advance Care Planning (ACP)
- Advance Decision to Refuse Treatment (ADRT)
- Advance Decisions (AD)
- Coordinate My Care (CMC)
- Decision Aid (DA)
- Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)
- Enduring Power of Attorney (EPA)
- Enduring Power of Guardianship (EPG)
- Goals of Care Document (GCD)
- Health Care Directive (HCD)
- Hospital Treatment Escalation Plan
- Lasting power of attorney (LPA) for health wellbeing
- PErsonalised Advisory CarE or (Proactive Elderly Advance CarE) (PEACE) plan
- Plan Ahead Program (PAP)
- Record of Best Interests (RBI)
- Shared Decision Making (SDM)
- State Administration Tribunal (SAT)
- Treatment Escalation Plans (TEA)

We included articles that addressed definitions of FCP and provided a description of what a 'Future Care Plan' should look like and incorporate, with regards to end-of-life care preferences and ACP.

Table 1 comprises of articles mapped to the research questions. Twenty studies addressed a description of what a 'Future Care Plan' should look like.

Kahana et al. (2020) defined FCP. This study involved semi-structured interviews focusing on racial differences in FCP in later life with the aim to encourage older adults, particularly racial minorities, to recognize and actively plan for their future care needs. Kahana et al. (2020) captured the definition from a qualitative study (Pinquart and Sörensen 2002) looking at factors that promote and prevent preparation for Future Care Needs. It referred to taking into consideration financial, medical and environmental support for future needs due to chronic illnesses or health events that threaten independence.

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Key Findings (continued)

Clarity on definitions are essential elements of patient-centred care. In 2017, a consensus definition was reached for advance care planning after a five-round Delphi study, designed by an international task force of 15 experts from eight countries and reported on in a 'State of the Science' Report (Rietjens et al 2017). “Advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.” (Rietjens et al 2017).

FCP is a broader term that includes advance care planning and additionally includes people who may not have decisional capacity at the time of planning. Planning for future care allows people to feel confident their wishes will be considered, if unable to participate in decision making. According to the Scottish NHS Inform, FCP may include:

- things you’d like people to know about you and what matters to you
- information about your family and other people who support you
- information about your health and care
- a carer information and support plan
- advice about your treatment and care from staff who know you
- decisions about CPR (if that is important for you)

Eleven studies attempted to define FCP, however in three of the studies (Benson & Mucci 2015, Kinley et al. 2018, Liang et al. 2023) the definition was unclear. **Table 2** presents study summaries and definitions captured from the included papers.

In the included literature, the following aspects/characteristics/components of FCP are described/highlighted/discussed:

- FCP is an opportunity for individuals to work with health and social care professionals to consider what matters most to them nearer the end-of-life, in terms of their wellbeing, and to explore their wishes for any future care or support that the person may need (Benson & Mucci 2015, Denvir et al., 2016, Denvir et al., 2014, Denvir et al., 2015, Huber et al., 2023, Janice et al., 2023 , Kinley et al., 2018, McIlfatrick 2018, Rietjens et al., 2021, Sivakumar et al., 2022).
- FCP can be relevant to every stage of life including those with diminished capacity at the time of information gathering and for whom a best interests approach should be followed, as defined by the Mental Capacity Act 2005 (Benson & Mucci 2015, Rietjens et al., 2021, Taubert & Bounds 2022, Taubert & Duffy 2024, Taubert et al., 2022).
- FCP discussions and dialogue should be recorded (including electronic patient records) and should be shared with those close to them, care givers, and professionals involved in their care. Such a plan may include the individual preferences about the nature, type and location of such services and may include discussions relating to individual’s medical treatment and wishes for end-of-life care (Huber et al., 2023, Meyers, et al., 2016, Sivakumar et al., 2022, Taubert & Bounds 2022, Taubert et al., 2023).
- FCP does not typically carry binding legal status unless there is a Lasting Power of Attorney or an Advance Decision to Refuse Treatment document (Liang et al., 2023, Taubert & Bounds 2022,).

Two papers referred to a Proactive Elderly Advance CarE Plan or a PErsonalised Advisory Care Plan (PEACE plan) (Benson & Mucci 2015, Kinley et al., 018). A PEACE plan refers to a document outlining the person's preferences or in some cases the best interest decisions and future planning as agreed by a General Practitioner and care/nursing homes.

Relevance of evidence

Though there are a variety of definitions, the literature shows that FCP involves conversations with family, carers, and professionals to discuss health and care preferences for future care needs.

Table 1. Articles mapped to the research questions

Q1. Is there a definition for 'Future Care Planning' in the existing literature?

Q2. Is there a description of what a 'Future Care Plan' should look like or incorporate with regards to end-of-life care and advance care planning?

Author /Date/ Country	Document type or study design	Q1	Q2
Benson & Mucci (2015), England, UK	Cross-sectional study	✓	✓
Denvir et al. (2016), Scotland, UK	Phase 2 randomised controlled trial		✓
Denvir et al. (2014), Scotland, UK	Qualitative interview and focus group study		✓
Denvir et al. (2015), Scotland, UK	Review		✓
Haire et al. (2024). Wales, UK	A quality improvement project		✓
Huber et al. (2023), USA	A mixed methods study comprising of a surveys and semi-structured interview		✓
Hyson et al. (2024), England, UK	No primary data -an overview of practice pointers		✓
Janice et al. (2023), Australia	Semi-structured interviews		✓
Jorgenson et al. (2016), USA	A retrospective chart review		✓
Kahana et al. (2020), USA	Face-to-face interviews	✓	
Kinley et al. (2018), England, UK	An audit & questionnaire	✓	✓
Lee et al. (2023), USA	A questionnaire & a survey	✓	✓
Liang et al. (2023), Australia	A single-centre quality improvement study	✓	✓
McIlfatrick et al. (2018) Ireland & UK	A mixed methods study comprising of a postal survey & interviews	✓	✓
Meyers et al. (2016), Canada & USA	A review - no primary data		✓
Rietjens et al. (2021), Nether-lands & UK	'State of the Science' Report - no primary data	✓	✓
Sivakumar et al. (2022), India & USA	An open forum		✓
Taubert & Bounds (2022), Wales, UK	Outline of strategic approaches in Wales - no primary data	✓	✓
Taubert & Duffy (2024), Wales & Scotland, UK	A letter - no primary data	✓	✓
Taubert et al. (2022), Wales, UK	A paper discussing definitions of ACP and clinical decision making - no primary data	✓	✓
Taubert et al. (2023), Wales, UK	A review of policies, guidelines and resources - no primary data	✓	✓

Table 2. Study Summaries and Definitions

Author, and Year	Study Objective	Definitions and Features
Benson & Mucci (2015)	To describe the PEACE (PErsonalised Advisory CarE) project, which aims to improve the End of life care experiences of patients admitted to a complex care ward (where most patients are frail with multiple comorbidities, usually including advanced dementia) who will be discharged to a nursing home and are anticipated to be in the last year or less of life.	"a medically led and facilitated planning process that can be undertaken with either patients of appropriate mental capacity or with those close to the patient when that person lacks the mental capacity to engage in care planning'"
Kahana et al. (2020)	To explore racial, demographic, and dispositional influences on thinking about and engagement in FCP among community-dwelling older adults.	"consideration of financial, medical and environmental supports for future needs due to chronic illnesses or health events that threaten independence"
Kinley et al. (2018)	To support care home staff to apply national policy on ACP in practice.	FCP may "incorporate the completion of a number of legal or advisory documents including: · A wishes and preferences document · Appointment of a Lasting Power of Attorney (LPA) · An Advance Decision to Refuse Treatment (ADRT)"
Lee et al. (2023)	To determine the feasibility and acceptability of the community-based group intervention, Plan Ahead program utilizing the reports from both participants and facilitators. In addition to examine program implementation by examining whether participants complete several future care planning activities after the program.	"Future Care Planning as consideration of health, financial, social, and environmental supports for future care needs due to chronic illness or health event that might threaten independence of older adults"
Liang et al. (2023)	Aimed at evaluating the effect of a multifaceted intervention on completion of ACP in a geriatric outpatient setting in Western Australia.	"Future care planning: any type of discussion about future care, such as ACP, ACD, EPA, EPG or SAT."
McIlfatrick et al. (2018)	To identify psychosocial factors associated with caregiver burden and evaluate the support needs of caregivers in advanced heart failure.	"a process of discussion between an individual, their care providers and often those close to them, about future care" ACP can reduce: · medical care and costs · enhance communication between patients and health care professionals · improve quality of care at the end of life
Rietjens et al. (2021)	No study aims/objectives, not primary data	"…an umbrella term to capture both ACP and best interest decision-making for individuals who lack decisional capacity from the beginning."
Taubert & Bounds (2022)	No study aims/objectives, not primary data	"The term future care planning is an umbrella term to capture both ACP, as well as best interest decisions for individuals who lack decisional capacity at the outset."
Taubert & Duffy (2024)	No study aims/objectives, not primary data	"Advance care planning requires decisional mental capacity from the patient at the outset—that is, when decisions about potential future treatments are discussed, weighed up, and views are written down. " "Future care planning, in contrast with advance care planning and anticipatory care planning, includes patients with diminished capacity at the time of information gathering, for whom a best interests approach should be followed. Ideally these discussions should happen with those who know the patient best, including knowledge of their likely views and preferences with regard to potential future interventions."
Taubert et al. (2022)	No study aims/objectives, not primary data	"FCP has been agreed as an umbrella term to capture both the advance care planning aspect (which, by the definition from the European Association for Palliative Care (EAPC), requires an individual to have decisional capacity at the outset), as well as best interest decisions for individuals who do not have decisional capacity regarding such aspects of their care at the start of a process."
Taubert et al. (2023)	No study aims/objectives, ot primary data	"It should be emphasized that DNACPR conversations form only one part of a what a wider advance care planning conversation should include, and NHS Wales has listed a host of resources that inform its Future Care Planning approach."

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Additional materials available upon request:

- Data extraction forms
- Search strategies
- List of excluded studies

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Disclaimer: Palliative Care Evidence Review Service (PaCERS) is an information service for those involved in planning and providing palliative care in Wales. Rapid reviews are based on a limited literature search and are not comprehensive, systematic reviews. This review is current as of the date of the literature search specified in the Review Methods section. PaCERS makes no representation that the literature search captured every publication.

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