York HS&DR Evidence Synthesis Centre

Advance care planning: a systematic mapping review of the evidence

Initial Scoping and Protocol

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1. Background

Although there is no universally agreed definition of advance care planning (ACP), the recently published NICE guideline NG142 "End of life care for adults: service delivery" (2019) defined it as "a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline".[1] An ACP discussion might include an individual's concerns and wishes, their important values or personal goals for care, their understanding about their illness and prognosis, preferences and wishes for types of care or treatment in the future and the availability of such treatment.

The NICE NG108 guideline (2018) "Decision making and mental capacity" stated that ACP should be offered to anyone who is at risk of losing capacity (eg a life-limiting illness) as well as those who have fluctuating capacity (eg mental illness).[2]

The first national guidance on ACP for health and social care staff in the UK was published in 2008[3] and revised in 2014.[4] Prior to this, terms such as "living wills" and "advance directives" were used in the UK. ACP plays a vital role in improving personalised care and the quality, consistency and responsiveness of end of life, mental health and dementia services. ACP features in the "The Ambitions for Palliative and End of Life Care" (2015) which provides a framework that sets out ambitions for national and local health and care system leaders to take action to improve palliative and end of life care.[5]

A number of recommendations relating to ACP are contained in the NICE NG97 guidelines "Dementia: assessment, management and support for people living with dementia and their carers" (2018).[6] These included offering early and ongoing opportunities to discuss the benefits and processes of ACP and giving individuals the opportunity to review and change any decisions made. NHS England also provide guidance (2017) for primary care providers and commissioners on ACP for people with dementia, regarding the wishes of the patient if or when capacity is impaired.[7]

The NICE guideline NG96 "Care and support of people growing older with learning disabilities" (2018) found there were no studies evaluating the effectiveness or cost-effectiveness of ACP for end of life care.[8] The NICE guideline NG142 "End of life care for adults: service delivery" made a number of recommendations relating to ACP.[1] It stated that service providers should develop policies to ensure that ACP is offered to adults who are approaching the end of their life and that systems and processes should be in place to support adults, carers and other people important to the person involved in ACP. It was also noted in the accompanying evidence review on ACP that the evidence was low or very low quality.[9]

The Health Service & Delivery Research Programme (HS&DR) asked us to investigate the effectiveness and cost-effectiveness of advance care planning for end of life care. This topic originally came from research recommendations in the NICE guideline NG96 on care and support for people growing older with learning disabilities,[8] although HS&DR requested that a broader population focus should be taken in the first instance.

It was agreed to adopt an iterative process to a mapping review of the evidence, including consultation with stakeholders at each stage, to ensure that what was produced would be useful and relevant.

The first stage was to scope and summarise existing evidence. The progress in Stage 1 and planned methods for Stage 2 are described below.

2. Stage 1 - Initial Scoping

1. Make contact with stakeholders
2. Search for any new primary studies relevant to NG96 "Care and support of people growing older with learning disabilities" which have been published since the searches for the guidance were undertaken[8]
3. Search for reviews of reviews (RoRs), systematic reviews (SRs) and cost-effectiveness studies of ACP in any population

(these activities were run concurrently)

2.1 Stakeholder Engagement

Stakeholders

Contact was made with NICE colleagues involved in relevant guidelines, as well as the NHS England (NHSE) National Clinical Director for End of Life Care.

Discussions

Discussions were held with colleagues at NICE who were involved in the guideline on End of Life Care for Adults, Service Delivery (NG142) and the guideline on Care and support of people growing older with learning disabilities (NG96). At the time of these discussions, the NG142 guideline was still in draft form but the final version is now published.[1] These discussions aimed to gather information about the topic from the perspective of these stakeholders, identify any specific research questions, and ascertain how the findings might be used.

The committee discussions for guideline NG142 started from the assumption that ACP should be undertaken, although stakeholder comments on the draft guidance questioned whether or not ACP is effective.[10] Important questions include whether ACP works and what are the best methods?

Colleagues involved in the NICE guideline NG96 which was published in 2018[8] reported that one of the review questions in the guideline was designed to locate evidence about the effectiveness, cost-effectiveness and acceptability (views and experiences) of end of life care for older people with learning disabilities. They found qualitative data about the aspects of care that people value and that people wanted (but didn't receive); however there was no evidence about the effectiveness of end of life care in this context, or about the cost-effectiveness. They were aware, though, of evidence that better access to end of life care for the general population is linked with benefits and cost savings (e.g. reduced emergency admissions and fewer deaths in hospital). Evidence for the general population also seemed to show that access to ACP might facilitate those outcomes. The guideline committee felt the same would be true among older people with learning disabilities but without any evidence were unable to recommend ACP. Instead their recommendations focussed on how end of life care should be managed, the kinds of conversations to have and how practitioners should work with the person, families and others.

These findings of NG96 led to the research recommendation to generate equivalent evidence on ACP about end of life care for people with learning disabilities as there is for the general population. This evidence could then inform any update of the guideline and give support to a strong, evidence based recommendation about using ACP in this context to support this specific population.

Discussions were also held with NHSE. Here, ACP is assumed to be good practice, what is considered more important is under what circumstances it works, how it should be implemented and understanding the nuances. Historically the focus of ACP was on planning and patient wishes, in particular place of death and Do Not Attempt Cardiac Pulmonary Resuscitation (DNACPR)

discussions. NHSE are moving towards personalised care and support planning with a focus on present, future (where ACP would sit), and emergency planning. Discussions in anticipation of loss of mental capacity can be distressing for people, so the risks and benefits need to be considered. For people with a diagnosis of dementia, ACP is particularly important as it is known that at some stage there will be a loss of capacity. For people with learning/intellectual disabilities, their level of capacity needs to be established. Every person should be offered the opportunity to have ACP but may not necessarily take it up. It is also important to consider how ACP conversations happen. Patients are waiting for health care professionals to begin the conversation and may not feel empowered to talk. Healthcare professionals may be less reticent to engage in discussions if patients have raised questions. There is some concern that metrics (such as the number of advance care plans on a register) may drive practice. It would be helpful to know to what extent such documents are used to support treatment plans when they are needed.

As a consequence of these discussions with key stakeholders we decided to map the existing evidence on ACP, to identify gaps in the evidence and highlight key issues. We also broadened the scope of the initial mapping stage to identify not only evidence of effectiveness and cost-effectiveness but also implementation, barriers and facilitators.

2.2 Searching for new primary studies published since the NICE Guidance

A search was conducted to identify any primary studies published since the searches for the NICE guideline NG96 “Care and support of people growing older with learning disabilities”.[8] A MEDLINE search was run replicating that used by NICE and combined the terms with "advance care planning". Search dates were from 2017 to 15th October 2019. A total of ten records were retrieved.

It was apparent that there were no new primary studies of a robust design to evaluate effectiveness or cost-effectiveness. One systematic review was identified which evaluated ACP in palliative care for people with intellectual disabilities.[11] There were six qualitative studies and the remaining records were case studies, a medical file review, and a consensus statement from a conference.

2.3 Rapid searches for evidence syntheses and cost-effectiveness studies

Searches

The following databases were searched for evidence syntheses: CINAHL, Cochrane Database of Systematic Reviews, Embase, Epistemonikos, Health Systems Evidence, MEDLINE, Prospero, Social Care Online. No geographic, language or date restrictions were applied.

A total of 1838 records were identified and loaded into EndNote bibliographic software. After deduplication there were a total of 847 records for screening

The following resources (which collect systematic reviews) were searched using the broad phrase “advance care planning”: Cochrane Database of Systematic Reviews, Epistemonikos, Health Systems Evidence, Prospero. The web resource Social Care Online was searched in a similar way.

The bibliographic databases CINAHL, Embase and MEDLINE were searched using a topic search combined (using AND) with a search filter to restrict the search results to systematic reviews.

In addition to the evidence syntheses, we also searched for primary cost-effectiveness studies. The NHS EED search used the MEDLINE database and combined a topic search strategy for ACP with a search filter designed to identify studies of cost-effectiveness.

All searches were carried out on 10th September 2019 except for the search of Prospero. This was conducted on 26th September 2019

Table 1 - Numbers of records identified per database

Database	Number of records identified
CINAHL	341
Cochrane Database of Systematic Reviews	11
DARE	1
Embase	318
Epistemonikos	162
Health Systems Evidence	78
MEDLINE	241
NHS EED	207
Prospero	79
Social Care Online	400

Selection process

Records identified by the searching process were screened by one reviewer on title and abstract for relevance against the following criteria:

Population: Adults (aged 18 and over) with any progressive life-limiting condition approaching end of life or likelihood of loss of mental capacity at some time, or their family members and carers; or health and/or social care practitioners involved in delivering care and support to adults with a life limiting condition approaching end of life or potential loss of mental capacity.

Intervention: Any form of intervention addressing ACP. Reviews solely addressing Advance Directives and Living Wills were excluded as these are only one component of ACP.

Outcomes: Any relevant to effectiveness and cost-effectiveness. As a result of discussions with stakeholders, this was broadened to include implementation and barriers and facilitators (See 2.2 Discussions with NICE and NHSE)

Study Design: Any form of evidence synthesis. Types of reviews that meet the criteria could include, reviews of reviews, systematic reviews of effectiveness; systematic reviews of implementation; meta-analyses; qualitative reviews or realist reviews. Reviews could include primary studies of any design. In addition, any economic evaluations of ACP were included.

One reviewer screened titles and abstracts for inclusion. Discussion was held with the review team where there was uncertainty regarding inclusion of a record.

Only information from Titles and Abstracts were used for determining inclusion and initial categorisation. Full texts of potentially relevant articles were not retrieved for the initial scoping, with the exception of the RoRs which were obtained for further investigation.

Data extraction

A review characteristics table was created in an Excel spreadsheet from the selected records' titles and abstracts. Data were extracted including review methods, intervention, ACP definition, population (setting, group, condition/circumstance), and outcomes (effectiveness, implementation/process, costs). Data were extracted by one reviewer. Discussions were held with the review team where there was uncertainty regarding a record.

Mapping of the data

Data from the spreadsheet were used to produce descriptive statistics for the key characteristics of the titles and abstracts (counts and percentages). These data were then used to provide a descriptive summary of the evidence.

2.2 Results of the initial scoping work

Summary of RoRs, Reviews, and cost-effectiveness studies

Of the 847 records screened, 129 were identified as potentially relevant, including two RoRs (in 3 publications) and three cost-effectiveness primary studies.

A brief summary of the characteristics of the potentially relevant RoRs, reviews and cost-effectiveness studies is provided below. This information was derived from the title and abstracts only of the records and therefore often only minimal information was available.

Reviews of Reviews

Full publications of the two RoRs (in 3 articles) were retrieved for closer examination.[12-14]

One RoR by Hall et al (2019) included systematic reviews of qualitative and quantitative primary studies to evaluate how end of life ACP discussions should be implemented according to patients and informal carers.[12] Fifty five reviews were included, published from 2007 to 2018.

Jiminez et al (2018)[13, 14] conducted a RoR aiming to identify relevant contextual elements, program features, implementation principles and outcomes of ACP to inform policy and practice. Eighty systematic reviews of both quantitative and qualitative primary studies were included published from 1994 to 2017.

The review questions, and inclusion criteria were broader than for our initial scoping review, for example systematic reviews evaluating the use of advance directives were included.

The reference lists from the RoRs[12-14] were examined and a note made of any relevant reviews to check that these had been identified in the initial scoping searches. Of those reported in Jimenez et al,[13, 14] 33 had been identified and included in the initial scoping searches, together with 31 reviews from Hall et al.[12] Fifteen of these reviews were reported in both Jiminez et al and Hall et al. We excluded a number of the reviews in the RoRs as they did not meet our inclusion criteria in terms of intervention (eg evaluating the use of advance directives or living wills), but all reviews that met our inclusion criteria had been identified in the scoping searches.

Reviews

In total 123 reviews were identified. These were published between 2003 and 2019 with 46 published since 2018.

The description of the reviews in the initial scoping varied with 75 labelled by authors as systematic reviews (including qualitative, quantitative and mixed method data). A range of other labels were used to describe the remaining syntheses including: critical review, evidence analysis, integrative review, literature review, qualitative meta-synthesis, realist review, technical brief and scoping review.

Most of the reviews included primary studies from multiple countries, but three reviews focussed specifically on USA data, two on Australian data, and one on data from the UK.

ACP was assessed in most of the reviews, although a few used different terminology such as end of life care planning, decision making or conversations.

Only 18 (15%) reviews provided a definition of ACP in the title or abstract. Most reviews (n=113, 92%) stated that ACP was the main intervention in the review, with the remainder reporting ACP as being part of a group of interventions, or the reporting was unclear.

As Table 2 shows, most of the reviews examined various aspects of effectiveness (n=68, 55%), experiences and perspectives of patients, carers and/or healthcare professionals (n=18, 15%) or barriers or facilitators to implementation (n=17, 14%).

Table 2 - Focus of reviews

	Number of reviews
Effectiveness	68
Experiences/perspectives of patients, carers and/or health professionals	18
Barriers & facilitators	17
Exploring Implementation factors	8
Costs/cost-effectiveness	5
Current practice	3
Cultural factors (eg ethnicity, religiosity)	1
Concordance between patient wishes and care received	1
Increase participation	1
Identifying gaps	1

Only 18 (15%) of reviews reported the setting in the title or abstract (Table 3).

Table 3 – Setting of reviews

	Number of reviews
Hospital	8
Community, nursing home or long term care facility	7
Primary care	3
Not reported	105

The largest proportion of reviews reported on patients only (n=48, 39%), health care professionals only (n=20, 16%), or both combined (n=12, 10%). Individual reviews included trained laypersons or volunteers. In total five reviews reported on different ethnic groups. Two reviews included homeless individuals. One review focused on social care workers. However 27% (n=33) of reviews did not report a specific population group in the title or abstract (Table 4).

Table 4 – population group

	Number of reviews
Patients only	48
Healthcare professionals (including GPs, nurses and other clinicians)	20
Patients, carers, and/or healthcare professionals	12
African American patients	2
Chinese patients	2
Homeless individuals	2
Trained laypersons/volunteers	2
Social workers	1
Ethnic minorities	1
Not reported	33

Table 5 shows that a range of patient conditions were examined in the reviews including end of life/life limiting condition (n=19, 15%), dementia (n=17, 14%), cancer (n=10, 15%) and chronic or end stage kidney disease (n=5, 4%). Other conditions reported were "older people", chronic respiratory or chronic obstructive pulmonary disease, heart failure or other heart condition, HIV, intellectual disability/learning disability, clinical deterioration, cognitive impairment, motor neurone disease. While 43% (n=53) did not report on specific patient conditions.

Table 5 - patient conditions

	Number of reviews
End of life or life-limiting condition	19
Dementia	17
Cancer	10
Chronic or end stage kidney disease	5
Older people	4
Chronic respiratory or chronic obstructive pulmonary disease	4
Heart failure or other heart condition	4
HIV	2
Intellectual disability/learning disability	2
Clinical deterioration	1
Cognitive impairment	1
Motor Neurone Disease	1
Not reported	53

Various outcomes were reported that could be grouped as effectiveness, process and implementation related, although not all abstracts reported the outcomes evaluated (38%, n=47), see Table 6. Barriers and facilitators were examined in 21 (17%) of reviews, closely followed by experiences, perceptions, knowledge and attitudes (n=20, 16%). A number of the reviews reported on completion of documentation rates (n=14, 11%), rates of admission to hospital (n=3, 2%), and participation rates (n=2, 1%). Other outcomes included those related to implementation (n=9, 7%), education (n=3, 2%), quality of life and/or satisfaction (n=2, 1%), while single studies reported on concordance between patient wishes and care received, and quality of care.

Table 6 – Effectiveness, process and implementation outcomes

	Number of reviews
Barriers and facilitators	21
Experiences, perceptions, attitudes, knowledge	20
Completion of documentation rates	14
Implementation	9
Admission rates (to hospital)	3
Education	3
Participation rates	2
Quality of life and/or satisfaction	2
Concordance	1
Quality of care	1
Not reported	47

Cost-effectiveness

Costs were examined in only eight records (6%) including five reviews and three studies of which two were protocols. All were variable in terms of methods used, topics covered, populations included and settings. A brief summary is provided in Table 7.

Table 7 – cost-effectiveness

	Number of reviews/studies
Reviews	5
Decision analysis	1
Cluster Randomised Trials (Protocols)	2

PROSPERO records

Nineteen records from the PROSPERO database were of potential relevance. Authors were contacted for any publications. Two authors provided publications which were included in the summary of reviews above. The remaining 17 were reported to be ongoing or about to be submitted for publication. These 17 records included a RoR, systematic reviews, and an economic analysis. Some were focused on specific populations eg patients with dementia, Parkinson's disease, stem cell transplantation, multiple sclerosis or organ failure. Authors proposed to evaluate a range of effectiveness, cost and implementation outcomes.

2.4 Summary conclusions from the initial scoping

Our update search suggests there are insufficient additional primary studies published since the NG96 "Care and support of people growing older with learning disabilities" guideline[8] to undertake a systematic review of research in this specific population.

Initial scoping suggests there are a large number of reviews evaluating ACP, with many recently published (47 published since 2018). Few details were provided in the titles and abstracts of the retrieved records resulting in only a summary of the evidence.

A number of ongoing reviews were also identified, some nearing completion or publication.

This initial scoping exercise together with the discussions with stakeholders suggests that a comprehensive map of the literature to assess the effectiveness, cost-effectiveness and implementation of ACP would be useful. While ACP is generally seen as good practice, a map of the evidence could inform future practice and research by attempting to understand under what circumstances ACP works, the best methods of ACP, how it should be implemented, barriers and facilitators to implementation as well as identifying gaps in the literature. It was decided to move forward to Stage 2 to provide a comprehensive map of the existing literature on the effectiveness, cost-effectiveness and implementation of ACP. This will involve undertaking more comprehensive searching, and then extracting and critically appraising data from relevant systematic reviews for which full papers will be obtained. The methods for Stage 2 are described below.

3. Stage 2 - Mapping the existing literature

Aim

To map the literature to assess the effectiveness, cost-effectiveness and implementation of ACP.

Based on the findings from the initial scoping work, a mapping review of the existing literature will be undertaken. Methods are reported in a linear format for ease of reading but some activities may

be conducted concurrently. The methods will follow on from those used in the initial scoping and an iterative, responsive approach will be used:

1. Formation of an advisory group
2. Identifying evidence syntheses and cost-effectiveness studies of ACP in any population
3. Identifying primary studies published since the most recent systematic reviews.
4. Mapping of the reviews, cost-effectiveness studies and recent primary studies

3.1 Advisory group

An advisory group will be formed comprising stakeholders and researchers. It is also intended to obtain public/patient involvement through Involvement@York, the patient and public involvement network and resource co-ordinated by the University of York. The aim of this involvement will be to ensure that relevant and important outcomes are considered, and to highlight areas and issues from a patient and public perspective.

3.2 Evidence syntheses and cost-effectiveness studies

Searches

Comprehensive searches will be run and will include further search terms identified during Stage 1 initial scoping.

Databases to be searched include CINAHL, Cochrane Database of Systematic Reviews, Embase, Epistemonikos, Health Systems Evidence, MEDLINE, NHS EED, Prospero, Social Care Online. No language or date restrictions will be applied.

The bibliographic databases CINAHL, Embase and MEDLINE will be searched using an ACP topic search combined (using AND) with a search filter to restrict the search results to systematic reviews.

The NHS EED search will use the MEDLINE database and combine a topic search strategy for ACP with a search filter designed to identify studies of cost-effectiveness.

The other resources will be searched using a topic only search strategy.

Selection process for evidence

Records identified by the searching process will be screened on title and abstract for relevance against the following criteria:

Population: Adults (aged 18 and over) with any progressive life-limiting condition approaching end of life or likelihood of loss of mental capacity at some time, or their family members and carers; or health and/or social care practitioners involved in delivering care and support to adults with a life limiting condition approaching end of life or potential loss of mental capacity.

Intervention: Any form of intervention addressing ACP. Reviews solely addressing Advance Directives and Living Wills were excluded as these form only one component of ACP.

Outcomes: Any relevant to effectiveness, cost-effectiveness or implementation.

Study Design: Any form of evidence synthesis. Types of reviews that meet the criteria could include: reviews of reviews; systematic reviews; meta-analyses; qualitative reviews or realist reviews. Reviews could include primary studies of any design. In addition any economic evaluation will be included. Conference abstracts will be excluded as it is not possible to critically appraise the robustness of the methodology used due to lack of information. Guidelines will be listed separately where they do not report detailed methodology to allow critical appraisal.

Two reviewers will independently screen titles and abstracts of records for potential inclusion. Full papers will be retrieved and two reviewers will independently screen for inclusion. Disagreements will be resolved through discussion or recourse to a third reviewer.

Data extraction

A review characteristics table will be created in an Excel spreadsheet. Data will be extracted including methods, intervention, ACP definition, population (setting, group, condition/circumstance), and outcomes (effectiveness, implementation/process, costs/cost-effectiveness). Data will be extracted by one reviewer and checked for accuracy by a second reviewer. Disagreements will be resolved through discussion or recourse to a third reviewer.

Critical appraisal

Critical appraisal of included evidence will be undertaken using relevant assessment tools and reporting standards. These will include the Database of Abstracts of Reviews of Effectiveness (DARE) database selection criteria for systematic reviews,[15] the RAMESES standards for the reporting of realist syntheses,[16] and any other methodology-specific tools. In addition, a relevant checklist will be used for economic evaluations.[17]

Assessments will be conducted by one reviewer, and checked by a second. These appraisals will inform conclusions about the internal and external validity of included research results.

3.3 Primary studies

Searches

There have been a number of recently published systematic reviews (2018/19) but we wanted to ensure no recent primary studies had been missed. The most recent reviews reported undertaking searches in early 2017 onwards, therefore we will search for primary studies from January 2017 to date.

Databases to be searched: CINAHL, Embase, MEDLINE, Social Care Online from 2017. No language or geographical restrictions will be applied.

Selection process

Records identified by the searching process will be screened for relevance against the following criteria:

Population: Adults (aged 18 and over) with any progressive life-limiting condition approaching end of life or likelihood of loss of mental capacity at some time, or their family members and carers; or health and/or social care practitioners involved in delivering care and support to adults with a life limiting condition approaching end of life or potential loss of mental capacity.

Intervention: Any form of intervention addressing ACP. Primary studies solely addressing Advance Directives and Living Wills were excluded as they are only one component of ACP.

Outcomes: Any relevant to effectiveness, cost-effectiveness or implementation.

Study Design: Primary studies of any design. Non-evaluative descriptive publications will be excluded but recorded for information.

Two reviewers will independently screen titles and abstracts of records for potential inclusion. We anticipate a large number of records to sift through so will explore using machine learning to prioritise the records to screen.

Full papers will be retrieved and two reviewers will independently screen for inclusion. Disagreements will be resolved through discussion or recourse to a third reviewer.

Data extraction

A study characteristics table will be created in an Excel spreadsheet. Data will be extracted including study methods, intervention, ACP definition, population (setting, group, condition/circumstance), and outcomes (effectiveness, implementation/process, costs). Data will be extracted by one reviewer and checked for accuracy by a second reviewer. Disagreements will be resolved through discussion or recourse to a third reviewer. Critical appraisal of the primary studies will not be conducted at this stage.

3.4 Mapping of the reviews, cost-effectiveness studies and recent primary studies.

A combined map will be provided including the review, cost-effectiveness and primary study evidence. Data extracted onto the Excel spreadsheet will provide descriptive statistics for key characteristics (counts and percentages). These will then be used to produce a map and descriptive summary of the evidence. This provides an overview of the extent and nature of the current evidence base relevant to ACP.

A "best evidence approach" will be adopted (eg, highlighting the best quality and most promising evidence) to inform future research and practice. Emphasis will be placed on reviews that use transparent or reproducible methods (as determined by the Database of Abstracts of Reviews of Effects criteria).[15] Reviews failing to meet these standards will be more briefly summarised, tabulated and referenced. A similar approach will be used for the cost-effectiveness studies, using appropriate tools. The primary studies will be summarised but not critically appraised as the aim is to identify those published since the most recently published reviews.

4. Dissemination

A report will be submitted to HS&DR. If appropriate, a summary of the research for publication in a journal article will be submitted, and an evidence summary developed to cascade implications for practice to key audiences (in consultation with the stakeholders). Alternative outputs and channels for the findings will be considered.

5. Timetable

	September	October	November	December	January	February	March
Stage 1 - Literature searching for initial scoping							
Stage 1 - Initial scoping and mapping exercise							
Stage 2 - Literature searching for mapping review of existing literature							
Stage 2 - Conducting mapping review							
Submission of report							

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