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A systematic review of the literature: To what extent are the medical treatment wishes laid out in preference tools respected?

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Foreword

An individual's right to play an active part in their treatment decisions at or near the end of life . even if they have lost capacity or are unable to communicate with their healthcare team . was enshrined in law in the Mental Capacity Act, 2005. The primary tool to exercise this right, an Advance Decision (also known as a living will or advance directive), enables people to set out in advance the treatment decisions they would chose to make, including the refusal of life-prolonging medical treatment. However as a relatively recent development, the understanding of this right . and its legally binding nature . is not yet widespread, either amongst the general public or amongst healthcare professionals.

As a charity concerned with helping individuals understand and enforce their rights at the end of life, Compassion in Dying is interested in increasing the use of Advance Decisions by people of all ages, and in ensuring that the medical profession has access to them when they are needed and understands their responsibility to respect them. Compassion in Dying was therefore seeking a clear evidence base to inform its policy and services in this area. Our initial analysis indicated that research into the use of Advance Decisions in the UK was very limited. We therefore decided to conduct a systematic review of published research to ensure that we were aware of all relevant UK evidence and to learn about evaluated practice from overseas. After an initial search and analysis of the literature we focussed on answering the question: *To what extent are the medical treatment wishes laid out in preference tools respected?*

We hope that this systematic review not only provides an analysis of good quality research evidence, but will also prompt the reader to think about how Advance Decisions and other similar tools might be used . and what work needs to be done to ensure they are used more broadly and effectively across the UK.

Compassion in Dying is a charity that focuses on research, education and advice on all aspects of the end-of-life process for adults. Our charitable objectives are to conduct research and to provide advice, information and guidance to all those affected by the end of life; including patients, carers and health professionals.

If you have any further questions or are interested in working with Compassion in Dying please contact Philip Satherley.

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To what extent are the medical treatment wishes laid out in preference tools respected?

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Key findings

- Evidence from the USA demonstrates that preference tools can be effective at ensuring patients' wishes are respected, but it is difficult to ascertain how effective such tools would be outside of planned end-of-life care.
- There was no evidence which demonstrated that preference tools have an *overall* negative effect on patient choices being respected. However, one study reported that those with and without a preference tool had their wishes respected to the same degree.
- No research from the UK was identified which answered the review question. However, lessons and evidence from the USA could impact on the development of UK practices.
- Research in the UK is needed to evaluate the effectiveness of medical treatment preference tools for use at the end of life in a variety of settings.

Content

This review will start with a general introduction into what medical treatment preference tools are, the context in which they are delivered and a justification for the project. Following this, the methodology for the systematic review will be detailed and evidence and key findings from the included studies presented. Conclusions, identified gaps in knowledge and suggestions for future research round up the paper.

Focussing the review question

During the assessment of studies initially selected for the review it became apparent that the initial systematic review question (What tools/activities are employed to support patient-informed decision making and choice in end-of-life care and what is known about their delivery and impact?) was too wide-reaching, and the evidence base too complex, to be meaningfully examined in one systematic review. A decision was taken to focus on a sub-set of studies which *evaluated the extent to which (medical treatment) wishes laid out in preference tools were respected*. This would ensure that concrete conclusions could be drawn about a very specific body of literature.

1. Introduction

End-of-life preference tools such as Advance Decisions, advance directives and living wills are written tools for guiding end-of-life practice. More specifically, they detail individual patients' preferences for care at the end of life should they lose the capacity to make decisions. Typically these tools include whether the patient wants to receive artificial nutrition and hydration, be resuscitated, and/or die at home, and can define levels of comfort care. For ease of reading, this paper will refer generically to these as preference tools unless referring to a particular study, where the language used to describe the tool will be used.

To date, research into the use of preference tools has focussed on their uptake, the systems they work in and their use by patients, healthcare professionals and proxies^{1 2 3 4 5 6 7 8 9}. Less research has been published which examines whether such tools have been acted upon and the patient has received the level of care they requested. A 2010 report from the King's Fund examined the Marie Curie Delivering Choice Programme (which aims to ensure the establishment of a comprehensive approach that is better able to fulfil individual patients' preferences for care as they near the end of their lives) and found that advance care planning (ACP) can ensure patients' wishes are respected and accommodated (unfortunately the publication does not report the level of detail needed for this systematic review)¹⁰.

Evidence from the USA in the 1990s predominantly indicated that preference tools have a limited role in medical decision-making^{11 12}. New federal legal rules, namely the Patient Self-Determination Act 1991 (PSDA), to ensure patient choices are recorded and acted upon had just come into force and a change in culture and attitudes towards care at the end of life was just emerging. The importance of the PSDA was brought to light by one particular case. A seven year legal battle was fought over the medical treatment of a woman (Terri Schiavo) who was in a vegetative state (she was incompetent when admitted to hospital and never regained capacity) in Florida¹³. If Terri had completed an advance directive as part of her normal healthcare regime (perhaps prompted by her physician) and her decisions had been documented on her medical records then potentially she might not have been kept alive artificially. This case prompted intervention by the federal government and sustained national and international media coverage, and raised awareness of advance directives and the use of proxies in the USA.

Evaluations conducted in the 1990s did not capture any changes in end-of-life practice and culture (if indeed there were any). However, there has been a growth in evaluations of these changes in care since the start of this 2000. There is no robust evidence-based consensus about whether preference tools are effective at ensuring patient treatment preferences are respected and, to date, no systematic review of what evidence there is has been conducted. In general, research evidence around end-of-life conversations and choices is limited¹⁴.

The majority of research which examines the use and impact of end-of-life preference tools has been conducted in the USA and most of the evidence contained in this review is from the USA (with one study also being conducted in Canada). In comparison there is little relevant work from the UK. What there is appears to focus on the use of a tool (also described as an approach in some of the literature) called Preferred Priorities for Care (PPC). This is specifically associated with the Liverpool Care Pathway (LCP) which is an integrated care pathway (ICP) for dying patients during the last days and hours of life. Significant investment has been made into the implementation of the PPC, LCP and Gold Standards Framework (GSF) (designed for delivering effective end-of-life care in primary and care home settings in the last year of life).

The aim of the review is not to focus on US evidence *per se* but to examine what preference tools work within healthcare system(s) and what lessons can be learnt for application to the UK.

2. Treatment preference tools

2.1. What are preference tools?

Research has indicated that doctors can have poor knowledge of patients' treatment preferences¹⁵. One way of ensuring that patient preferences at the end of life are recorded and can impact on their care is to document them in written and/or electronic form. People complete preference tools before they lose capacity and the details contained in the document should control decision making (this is especially the case where a legally binding Advance Decision has been used). Like any tool or guidance for practice, they are only as good as the system in which they are embedded.

Research has found that patients who participate in end-of-life decisions have positive experiences¹⁶ and those who passively participate often receive unnecessary treatment and might suffer a bad death¹⁷.

Research into guidance tools (such as ICPs) has found that their effectiveness is dependent on a series of factors such as the care setting, whether the healthcare professionals have bought into the tool and patient involvement¹⁸.

2.2. Historical and international context

In the UK, preference tools (commonly known as Advance Decisions, advance directives or living wills) are either advance decisions to refuse medical treatment and/or Lasting Powers of Attorney. In 2007, in England and Wales, Advance Decisions were given statutory force under the Mental Capacity Act 2005 (MCA) although they were previously valid at common law. Advance Decisions are binding at common law in Scotland and Northern Ireland and should be taken into consideration when making end-of-life decisions. The MCA also now allows adults with capacity in England and Wales to make a Lasting Power of Attorney (LPA); this allows a person to appoint an individual(s) to make decisions on their behalf, should they lose capacity. LPAs are registered with the Office of the Public Guardian.

As yet, there is no required system for recording whether a person has an Advance Decision, and what it says on a patient's medical records. The End of Life Care Strategy (2008), applicable to England, sets out aspirations and suggestions for end-of-life care rather than detailing specific models to be followed and evaluated.

*"In some cases people may want to make an advance decision to refuse treatment, should they lack capacity to make such a decision in the future. Others may want to set out more general wishes and preferences about how they are cared for and where they would wish to die."*¹⁹ (pg 12)

Clearly an evidence-base is needed to support the promotion, documentation and respecting of Advance Decisions preferences. Strategies similar to the End of Life Care Strategy have been introduced in Scotland²⁰ and Wales²¹.

In the USA the PSDA requires that all healthcare institutions in receipt of federal funding, e.g. Medicare and Medicaid (a social insurance programs administered by the United States government, providing health insurance coverage to people who are aged 65 and over) inform patients upon admission of their right to make decisions concerning medical care such as the right to formulate an advance directive. Such information should be documented on the patient's medical records. Preference tools (commonly known as advance directives) have two main formats . either an advance statement of preferences for care or the nomination of a healthcare proxy to make decisions on their behalf. In the USA the term advance decision or living will often covers documents which are meant to be used with the advice of an appointed surrogate and those which are stand alone²².

2.3. Preference tools which have been evaluated and included in the review

Preference tools which were used in studies included in the review are reported below.

USA and Canada

Physician Orders for Life-Sustaining Treatment (POLST) This is an end-of-life tool, which is usually embedded with a POLST paradigm (dedicated end-of-life care system) which documents patient's medical treatment wishes. It is designed to convert patient preferences for life-sustaining treatments into immediately actionable medical orders and to be transportable between care settings²³. An attending physician or nurse-practitioner discusses options with the patient and signs the form (thereby creating a medical *order*) with the patient present. It is aimed at those in end-of-life care programmes, the chronically ill and those in a frail state. This was used in three studies in the review.

Generic advance directive/living will These gather information on what medical treatments the patient wants/refuses when they have lost capacity. Typically

these include decision-questions on Do Not Attempt Resuscitation (DNAR), Do not Intubate (DNI), levels of artificial nutrition and hydration, hospitalisation orders and antibiotic treatments. These are completed in a number of ways, either with a healthcare professional present or by the patient themselves. Different US states have different advance directive forms and procedures. They can be completed at any stage and are not dependent on the person having a chronic condition etc. These were used in four studies in the review.

Let Me Decide advance directive This is an example of locally developed advance directive tools which are common across the USA and Canada (although only one study which fitted with the objectives of the review was conducted in Canada). This specific tool was developed in 1988 and has had consistent support from residents and healthcare workers²⁴. Individuals can choose levels of care for life-threatening (from intensive to palliative), nutrition and cardiopulmonary resuscitation (CPR) etc. The form can be used by the individual or a proxy to inform care.

UK

Preferred Priorities for Care (PPC) This was formerly known as the Preferred Place of Care, was launched alongside the Liverpool Care Pathway and was designed to capture information about where patients would like to be cared for at the end-of-life. It does not capture information on medical treatment options and is not legally binding. Rather it records patient care wishes, what services are available and any reasons for change in the care trajectory. In theory, lessons learnt would influence service development.

PPC is reliant on good coordination between healthcare professionals and knowledge of what services can be provided. Concerns about the levels of care available to support patient wishes, especially in the community setting, have been expressed by healthcare professionals²⁵.

2.4 The implementation of preference tools

Preference tools are integrated into healthcare systems differently. In England and Wales, tools such as Advance Decisions²⁶ have been developed and then placed into the wider healthcare system with little or no national policy to support their implementation or recognition (although the End of Life Care Strategy and recent General Medical Council guidance on end-of-life care have gone some way to recognise their importance¹⁹) in the hope that they will work. In the USA there has been a national and local approach to embedding preference tools in practice. The PSDA has gone some way to ensuring national coordination, and at the local level there have been numerous schemes to develop and implement appropriate preference tools within end-of-life care models.

2.5. Numbers of people using preference tools

It is difficult to calculate exact numbers of people who have recorded their end-of-life preferences. According to the literature from the USA, the reported figures for people who use preference tools vary. In one national study 71% of decedents had written an advance directive²⁷. Another local study found that 90% of people receiving end-of-life care within a specific care system had completed the preference tool. Other figures suggest a much lower rate of between 20-30% of use by the wider population in the USA^{28 29}. It has also been reported that people who died at home or in a nursing home were more likely to have a preference tool than those that die in hospitals (i.e. they were more likely to have planned their care)³⁰.

Data on numbers of people using such tools in the UK is unclear. A poll found that 11% had completed an Advance Decision³¹ and data from the Office of the Public Guardian reports that 23,360 people had appointed a Lasting Power of Attorney for Health and Welfare in the first 18 months that they were available³².

3. End-of-life systematic reviews

To date, published systematic reviews have examined several areas of research concerned with end-of-life choices and the tools for making these choices. Topics covered have included improving outcomes in caring for the dying³³, factors that influence death at home³⁴, improving transitional care between nursing homes and hospitals³⁵, whether surrogates make the right decisions³⁶ and improving the uptake and completion of preference tools^{37 38}. To the best of our knowledge no systematic review has been conducted which examined whether the treatment wishes detailed in preference tools had been respected.

Overall, the body of literature which examined end-of-life preference tools contains conflicting conclusions as to whether preference tools ensure that patients' wishes are acted on. An article published in 2004 stated that *"empiricists cannot show that advance directives affect care"*, but recent evidence appears to demonstrate that in the right circumstances preference tools can ensure that patients' wishes are met³⁹.

4. Methodology

4.1. Pilot search

A pilot search for literature was conducted which determined that there were published studies which might address our review question.

4.2. Inclusion and exclusion criteria

Studies were included and excluded from the review based on the following pre-determined criteria.

4.2.1. The presence of a patient-directed tool

On reviewing the literature it was decided to only include studies where there was explicit reference to a preference tool. Where tools were examined as part of

a wider programme such as an ACP but were analysed separately there was the potential for them to be included in the review, if enough detail was given about the preference tool. Advance Care Planning programmes not linked to a specific preference tool were not included.

4.2.2. Care setting

Studies were not excluded based on the care setting (e.g. nursing home, acute hospital, community).

4.2.3. Study design

Studies were not excluded according to the methodology they employed. Traditionally, systematic reviews only included Randomised Control Trials (RCT) as these are considered the best evidence for examining interventions and programmes, although this has changed in recent years with the recognition that RCTs and other methods are appropriate. A preliminary examination of the literature indicated that RCTs were used alongside other methods (for example, the examination of medical records).

4.2.4. English language

Only studies published in English were included in the review.

4.3 Locating, organising and screening studies

4.3.1. Search strategy

A list of key words and Medical Subject Headings (MeSH) were generated during the pilot search. MeSH is a controlled vocabulary system which is used to index studies on electronic databases. Key words can be used as a less accurate (although essential in order to capture non-indexed studies) way of locating studies. Key words and/or MeSH headings were used depending on the sophistication of the database being used. Themed areas were combined in various ways depending on the database, for example DNAR generated thousands of references so was combined with end-of-life and decision whereas Advance Decision was searched for as a stand-alone search term. The following keywords and MeSH were used in the search:

1. End of life

End of life
Palliative/Palliative care/Palliative treatment
Terminal care
Terminal illness
Terminally ill patients
Death and dying
Chronic illness
Long-term condition

2. Decision making processes

Decision making

Patient-informed (e.g. patient-informed palliative care)
Informed consent
Patient education
Patient empowerment
Patient-led
Patient satisfaction
Decision support techniques

3. Tools and activities

Advance Care Plan
Care plans/planning
Advance Decision
Advance directive
LPA/Lasting Power of Attorney
Proxy
Physician-patient relations
Resuscitation orders/DNAR (and variations on this)
Withholding treatment
POLST
Patient preferences

4.3.2. Databases used

The following health and social care databases were used to locate studies: Medline (social and healthcare), EMBASE (medical), British Nursing Index, PsycINFO (psychology), AMED (allied health professionals) and ASSIA/Sociological Abstracts (social science orientated). A database of grey literature (unpublished reports) was not included in the package of databases we subscribed to so could not be accessed.

An additional search was conducted to locate material on the PPC (using Medline, Embase and google/google scholar).

4.3.3. Storing references

Where possible libraries generated from the search were stored electronically in Endnote. This allowed for abstracts and titles to be filtered and organised effectively.

4.3.4. Screening of abstracts

Systematic reviews are reliant on research papers having clear abstracts which detail the content of the paper. Abstracts were assessed to see if they were relevant to the review. Firstly, studies had to state that they were examining a preference tool and its impact on end-of-life care. Secondly, abstracts were examined to identify those that *explicitly* or *implicitly* stated that the study examined the extent to which preferences were acted upon. Following this, full papers were read if they appeared to answer the review question.

4.3.5. Numbers of papers located

The search strategy located 3,578 references from the electronic databases and additional searching (through bibliographies etc.). These were then checked for relevance which resulted in 450 studies of potential relevance. When these were checked in more detail for congruence with the review question and methodological rigour 8 were selected for full appraisal.

4.3.6. Assessing the relevance and quality of studies

Findings from the study were examined for relevance. If they answered the question at hand they were critically appraised for quality. This was done using standard critical appraisal questions from the Critical Appraisal Skills Programme (CASP). They provide critical appraisal tools for a variety of study types (from RCTs to qualitative), all of which can be accessed at <http://www.sph.nhs.uk/what-we-do/public-health-workforce/resources/critical-appraisals-skills-programme>. Additional questions on the context of the study or intervention and practice setting were asked.

4.3.7. Principle and secondary reviewers

Philip Satherley was the primary researcher and located and selected studies for review. Quality checks and abstraction of data were conducted by the principle research, with a random sample of papers reviewed for quality and data abstraction by Davina Hehir.

4.4. Data extraction

Key data on inputs (tool) and outputs (the extent to which preferences were acted upon) of the evaluation were extracted. Where there is sufficient heterogeneity between studies, data has been pooled. Where this was not possible, data has been reported as a narrative, and conclusions drawn about what the studies indicate as a whole.

Ideally, contextual details about the healthcare system in which studies exist would be present in evaluations of services. By this we mean whether there is an examination of the causal relationship between a programme/intervention (in this case preference tools) and the outcome, and whether an unidentified external variable has impacted on the relationship. In other words, what factors other than the intervention (preference tool), have led to something being a success or failure. Studies conducted in this manner are known as *realistic evaluations* and they are useful to explore *what works for whom and in what circumstance*⁴⁰. This means that practitioners and policy makers can assess if the phenomenon or tool has application to their situation. Unfortunately, this level of detail is not reported in most evaluations.

4.5. Levels of evidence

Clarifying the strength of the evidence contained in studies is traditionally guided by what study design is employed alongside methodological quality.

Methodological quality *not* study design was used to determine inclusion in the review, as our experience demonstrated that research in this area was likely to be conducted using a variety of research methods. All studies for inclusion in the review were of sufficient methodological quality and individual studies have not been graded according to study design.

4.6 Evidence types

For the purposes of this review it was decided to organise the studies according to evidence *type*, i.e. the relationship between preference tool and *type* of compliance reported. This system was developed in hindsight, based on the included studies, rather than using a pre-determined rule. This is not a hierarchy of evidence, but is a guide for the reader.

Evidence types:

- 1) Association between *specific inputs* (specific preferences detailed in tools) and clear outputs (e.g. was the \neq do not hospitaliseorder adhered to?).
There is a clear association between specific items on the preference tool and whether they were adhered to.
- 2) Association between the presence of a tool and whether patient preferences had been acted upon. *The author reports the extent to which overall compliance with wishes was adhered to – does not necessarily demonstrate that the preference tool was consulted in 100% of cases.*
- 3) Association between the presence of a preference tool (or specific items within the preference tool) and outcome such as place of death or whether the patient was transported at the end-of-life. *The author reports on the preference tool and an outcome not detailed in the tool - does not necessarily demonstrate that the preference tool was consulted in 100% of cases.*

5. Results

5.1. Summary of study types, settings and participants

Eight studies addressed the review question and were of sufficient quality for inclusion:

- i) Five studies analysed medical records
- ii) One study conducted a longitudinal analysis of medical records to compare practice
- iii) One study gathered data by interview or survey with family members/informants of the deceased
- iv) One study was an RCT

All studies which qualified for inclusion in the review were conducted in the USA apart from one which was conducted in Canada. These make up the bulk of the

review and are concerned with medical treatment wishes. This USA research activity is reflective of the work (and its evaluation) that has been going on since the PSDA was passed in the early 1990s. Typically, studies focussed on older patients/participants and non-traumatic deaths, or those whose death trajectory was one of a slow gradual decline

There was no heterogeneity between studies. Whereas some studies reported the extent to which specific treatment preferences were followed, others reported more general choices followed and others reported associations between the presence of a preference tool and treatment and/or place of death. Data was also analysed and presented differently across the studies. Therefore, statistical pooling could not be conducted. Overall conclusions were drawn by examining the evidence study-by-study, indicating the extent to which preferences were measured, acted upon and then by summarising key points.

Studies were set in a variety of care settings. The main focus was on nursing facilities or the community, with less focus on examining traditional hospital settings (which were analysed alongside other care settings in two papers). The majority of studies did not *just* examine whether patient preferences had been acted upon. This question usually formed part of a wider study which examined issues such as patient satisfaction with preference tools, what treatment options patients tended to select and what particular treatment preferences were associated with others.

The studies which were suitable for inclusion in the review were overwhelmingly conducted in the community and nursing home/facility settings. This reflects where researchers and policy makers' interests have been focussed over the past ten years and where novel systems for ensuring patient choices can be respected have been developed and evaluated.

Audit and research from (from England, although similar work is going on in Wales) which reports on PPC evaluations has been included in section 5.2.4. These do not detail medical treatment wishes, rather preferred places for care/dying.

5.2. Table and narrative results

This section provides a table and narrative summary of the included studies. Contextual details are reported where provided by the author. Studies have been organised according to the extent to which the preference tool was respected. Due to levels of detail reported, work which reports on the PPC has not been presented in the table.

5.2.1. Table of results (Appendix 1)

Information presented in the table summarises key findings from the eight papers. It does not present statistical findings in any detail as these are reported in the narrative section below.

5.2.2. Conclusive evidence. The presence of a preference tool led to patient wishes being acted upon

Eight studies are included in this section (including two papers which drew from the same large-scale study, but analysed different aspects and data). Evidence is from the USA apart from one Canadian study. Studies were conducted in nursing facilities, hospice programmes, nursing homes and two community programmes for the care of older adults. Only one study included traditional hospitals and was conducted across all healthcare organisations in a county (which included long-term care, hospitals, home health agencies and a county health management organisation). The delivery of end-of-life care in these types of settings (with the exception of traditional hospitals) is often more sophisticated than in others, with dedicated education programmes and initiatives to engage with service users. Preference tools and practices around patient choices can also be better managed and planned in these environments.

Hickman *et al* (evidence type 1) conducted a large-scale comparison of deceased nursing facilities residents' use of POLST⁴¹, compared to traditional practices (living will, CPR order or no documentation of wishes) and examined what treatment preferences were acted upon. Specific comfort care preferences were analysed in detail (resuscitation and artificial nutrition data preferences were too small to analyse).

POLST orders restricting medical interventions were associated with less use of life-sustaining treatments. Residents with a POLST indicating *comfort care only* were 42% less likely to receive life-sustaining medical interventions than residents with POLST *limited interventions* ($p = 0.03$) and 67% less likely to receive life-sustaining medical interventions than residents with POLST *full treatment orders* ($p = 0.004$). Similarly, residents with POLST *comfort only care* orders were 59% less likely to receive life-sustaining treatment than residents with traditional DNAR orders ($p = 0.001$) and 71% less likely than those with traditional full code orders (where everything is done to keep the patient alive) ($p < 0.001$).

Using the same data set (but analysing different variables), Hickman *et al*⁴² (evidence type 1 and 2) examined the use of the POLST tool within the hospice setting (in the USA, hospice care is mainly delivered in the home or community rather than in specific hospice buildings). Preferences for treatment limitations were respected in 98% of cases and no one received CPR, intubation, intensive care or feeding tubes who refused it in their POLST. Further analysis found that in 99% of cases the withholding of CPR was in accordance with the POLST order. Patients with orders for *comfort care only* were less likely (no p value given) to experience hospitalisation and intravenous fluids than patients with orders for *limited* or *full medical interventions* (OR = 3.74, 95% CI = 1.81-7.72).

POLST is specifically designed for people with progressive chronic illness or frailty and its use has been widely supported by healthcare professionals, with training provided and strong uptake as a model for working. Alongside this, POLST is especially useful in the transportation of patients (transportation and emergency staff can refer to the signed physician's order as opposed to a list of treatment preferences).

A small-scale study by Pekmezaris *et al*⁴³ (evidence type 3) examined the medical records of deceased nursing home residents for the impact of advance directives on place of death (hospital or nursing home). Results indicated that the existence of an advance directive in the patients' records impacted on the decision to transfer the patient at the end of life. Significantly higher proportions of patients dying in the nursing home had a DNR order compared to those in the hospital ($X^2 = 20.34$, $df = 1$, $p = 0.000$). Significantly higher proportions of patients dying in the nursing home had a Do Not Intubate (DNI) directive in their chart as opposed to those dying in hospital ($X^2 = 6.69$, $df = 1$, $p = 0.010$). Significantly higher proportions of patients dying in the nursing home had do not artificially feed/hydrate directives as compared to those dying in hospital ($X^2 = 6.43$, $df = 1$, $p = 0.011$, $X^2 = 3.99$, $df = 1$, $p = 0.050$). The author also notes that none of the patients with a Do Not Hospitalise (DNH) directive in their chart was found to have died in the hospital.

Molloy *et al*⁴⁴ (evidence type 3) conducted an RCT involving residents ($n = 1,292$) in nursing homes across Canada which compared the Let Me Decide Advance Directive (LMDAD) with the control - continuing prior policies concerning advance directives (which did not prescribe any particular advance directive) from a patient satisfaction and health economic perspective.

The intervention included workshop training and an audit of the tools' implementation. Before the intervention, hospitalisations, hospital days and mortality rates were similar for the intervention and control homes. After the intervention period the adjusted risk of hospitalisation was lower in the intervention home residents than the control home residents (0.27 vs. 0.48 mean hospitalisations per patient, $p = 0.001$). Intervention residents also had a lower mean number of hospital days than controls (2.61 vs. 5.86, $p = 0.01$). Mortality rates in the intervention and control nursing homes were similar (24 % vs 28%, $p = 0.20$).

Schamp & Tenkku⁴⁵ (evidence type 2 and 3) examined medical records for both present directives and advance directives (collectively known as a Pathways Tool). This was within a model for older person care called the Program for All-inclusive Care of the Elderly (PACE), where patients' preferences were used to map their care onto specific pathways - longevity, function and palliation. Compliance with end-of-life wishes for deaths before the introduction of the Pathways Tool was 72%, compared to 96% after its implementation ($p < 0.05$). Although dying at home was not a specific item in the Pathways Tool, deaths at

home rose from 24% to 65% ($p < 0.001$) and there was a rise in participants who chose the palliative/comfort care pathway (9% vs 53%).

PACE is aimed at community-dwelling older adults and incorporates specific training for healthcare professionals. More specifically the aim of this project was to improve the culture of patient-centred care and test an innovative method for recording acting on present and advance healthcare wishes.

Degenholtz *et al*⁴⁶ (evidence type 2 and 3) studied the relationship between having a living will and place of death. Having a living will was associated with a lower probability of dying in a hospital for nursing home residents and people living in the community. A living will was present in 40% of cases. Compared to those without a living will, decedents with a living will were less likely to have received all life-sustaining medical treatments (5% vs 30%; $p < 0.001$), more likely to have had treatments withheld (65% vs 29%; $p < 0.001$) and more likely to have had efforts made to keep them comfortable and pain-free (94% vs 86%; $p = 0.005$).

For people living in nursing home, the probability of in-hospital death decreased from 0.35 (CI, 0.23 to 0.49) to 0.13 (CI, 0.07 to 0.22) (CI of 95% not stated). For people living in the community the probability of an in-hospital death decreased from 0.65 (95% CI 0.58 to 0.71) to 0.52 (95% CI 0.42 to 0.62). Living wills are associated with dying in a place other than hospital. This doesn't demonstrate that they work as a blanket tool but does indicate that where they are present they can influence place of death. Data was gathered from 1993 to 1995 (after the introduction of the PSDA).

Hammes *et al*⁴⁷ (evidence type 2) conducted a longitudinal examination of the use of an ACP system/preference tools and reported the historical development of the system. This was called the La Crosse Advance Directive Study (LADS) and data was gathered in 1995/96 (LADS I) and again in 2007/08 (LADS II).

Participants died in a mixture of home, hospital, inpatient hospice and long-term care facilities. Whilst this is a study of an advance care plan, within what the authors describe as a *clinical microsystem* (carefully planned, inter-professional and targeted at end-of-life patients, in this case in one county), the use of preference tools (predominantly POLST, but also generic advance directives and living wills) dominates the programme and system. This microsystem is reported as being a collaborative effort across La Crosse (Wisconsin) healthcare organisations. It focuses on patient-centred end-of-life care, ensuring patient records are understandable by all stakeholders, are transported across settings effectively and are reviewed and acted on at the right time.

The use of all preference tools was high (85% in LADS I and 90% in LADS II), with 95% available in medical records at the location of death in LADS I and 99.4% in LADS II. This demonstrates longitudinal consistency in recording and

access to patient preferences. Consistency between preference about CPR and hospitalisation and medical decisions at the end of life was not different between LADS I and II. In LADS I preferences regarding CPR and hospitalisation were consistent with treatment in 98% (530/539) of cases and in LADS II the consistency was 99% (380/382) ($p = 0.14$).

The authors reported several advances in practice during and in between data collection, such as the introduction of a specific power of attorney document in Wisconsin in 1998 and a programme for storing electronic medical records which detail all advance directive information ranging from '*the patient has decided to be a full code*' (full code means to do everything possible to save the patient's life) to '*the patient has decided to take a palliative approach to treatment, and wishes no treatment to sustain life*'. Preference tools in LADS II were created a median of 3.8 years before death, compared with 1.3 years in LADS I ($p < 0.01$) (although it must be noted that POLST, which was the most-used preference tool, are typically created closer to time of death).

5.2.3. Inconclusive. The presence of a preference tool did not lead to patient wishes being acted upon any more than with normal end-of-life care

One study is included in this section and examined nursing home, hospital and home settings.

Teno *et al*²⁷ (evidence type 2) conducted a large-scale study which examined where patients with advance directives died (nursing home, hospital and home) and the levels of care they received. Deaths (not expected, somewhat expected and very much/extremely expected) were examined by asking bereaved family members or other knowledgeable informants. The research did not measure whether specific preferences were followed through, rather it reported on the presence of an advance directive and whether care was *inconsistent* with wishes. 72.4% of those with an advance directive had specific wishes and 32.1% without an advance directive had specific wishes. Care was reported as being inconsistent with wishes in 9.7% of cases where a patient had an advance directive, and in 9.5% of cases where no advance directive was reported. Similarly, amount of life-sustaining treatment delivered too much and just right was similar for those with (5% and 86.7%) and without an advance directive (3.7% and 81.7%) (no p values reported). Not enough life-sustaining treatment was reported for 8.4% of those with an advance directive and 14.7% of those without an advance directive. Evidence from this study is inconclusive as to whether the presence of an advance directive is any more effective at ensuring patient preferences are adhered to than where no official documentation is used.

Where an advance directive was present the patient received less life-sustaining treatment in the last month of life and was less likely to die in an intensive care unit (11.8% vs 22%), to be on a respirator (25.6% vs 36.7%) or to be using a feeding tube (17.3% vs 26.8%). Where no advance directive was present (but specific wishes had been noted) patients were less likely to die in intensive care

(14.1% vs 19.6%, $P = 0.002$), to be on a respirator (29.7% vs 42.6%, $p = 0.02$) less likely to have a feeding tube (18.5% vs 30.2%, $P = 0.09$) and more likely to die at home with hospice services (20.7% vs 11.6%, $P < 0.001$).

5.2.4. Preferred Priorities for Care tool (UK)

There is a body of evidence from the USA which focuses on medical treatment preference tools and whether patient wishes have been respected. This has not been replicated in the UK; however there is a small body of evidence which has examined the effectiveness of the PPC tool (or approach). Whereas the US literature examines medical treatment preferences, the PPC captures patients' priorities for care (essentially, where they would like to be cared for at the end of their life). For these reasons we have separated the evaluation of the PPC from the USA literature. Current literature on the PPC is predominantly audit or small-scale research and evidence which indicates that the PPC tool/approach may be working.

Wood⁴⁸ examined the first 100 cases where a PPC assessment had taken place in two NHS PCTs in North West England (2002-05). Of these 100 cases, 73 wanted to die at home, and 68 (78%) were able to do so. This is in contrast to the 58% of deaths which take place in NHS hospitals, 18% at home and 17% in care homes in England¹⁷. The authors report that in 30% of cases, assessment and recording of PPC took place close to death, so that it may not have been possible to transfer patients from home to hospital which may have skewed the figures. A similar audit conducted by West Essex NHS reported that 82% of patients expressed a preference to be cared for at home in the end-of-life stage and that 83% of patients died in their preferred place⁴⁹.

Newton *et al*⁵⁰ evaluated the use of 211 PPC documents. Of the 182 patients who died, 116 (64%) wanted to die at home and 81 (70%) of these achieved this. In total (of all stated preferences), 129 (71%) achieved their preferred place of care. If hospice at home professionals were involved then 76% of patients achieved their PPC. If the document was coordinated by a community district nurse or Registered General Nurse (RGN), 76% of patients achieved PPC, and if it was initiated by other groups of staff 64% of patients achieved PPC. Essentially this study examines the healthcare professionals (who assisted patients when they filled out the PPC tool), rather than the tool as a stand-alone intervention.

Duke and Fisher⁵¹ examined the impact of the hospital discharge team nurses (HDTN) (made up of experienced community and hospital nurses) on the achievement of the PPC. The study reports on the successful application of the PPC, with 36 of the 39 cases achieving PPC. Within this study, 18 out of 21 patients who wanted to be discharged to the home achieved this type of discharge. All nursing home and hospital requests were respected. A dedicated HDTN was developed specifically to implement the PPC approach and the authors conclude that this coordinated support is an effective intervention for

managing and achieving PPC. This suggests that the tool, or approach, is only as effective as the team or system which implements it.

This section on the PPC is not a systematic review of this particular tool; rather it gives an indication of its success. Little peer-reviewed research has been published and, furthermore, the PPC does not document medical treatment preferences. Therefore, this PPC evidence has not been incorporated with the main findings from the systematic review. Evidence appears to suggest that this tool is fulfilling its remit and patients are being cared for in the place of their choice, but that the delivery of care to a patient in their preferred place is reliant on dedicated staff being involved, and an awareness of what services are available and appropriate training.

What does not appear to have been researched or explored in the literature is the potential for the emphasis on the PPC (and protocols associated with ensuring it is reached) to result in inappropriate and sometimes distressing conversations with patients who are not yet ready to discuss their death, e.g. when a local protocol requires the palliative care professional to ask about this issues on admission in the first meeting with the patient. Large-scale evaluation needs to be conducted to further test the PPC.

6. Conclusions

The vast majority of academically published evidence which addressed whether preference tools were respected was from the USA. This is not surprising given the emphasis on patient rights and end-of-life care in the USA.

Such developments (Advance Decisions being given statutory force by the Mental Capacity Act 2005, the End of Life Care Strategy and similar initiatives, and the General Medical Council's guidance on Treatment and care towards the end of life: good practice in decision making) are more recent in the UK. This is reflected in a lack of evidence found which was of relevance to the review.

6.1. USA (and Canada)

Evidence from this review demonstrates that currently preference tools work best when end-of-life care can be planned. When they are applied in settings such as nursing homes or within specifically developed models for end-of-life care they are effective at ensuring patient preferences are acted upon. Evidence for more general hospital settings is less conclusive.

Evidence from studies set in nursing facilities, hospices and community settings demonstrates that such tools can have a positive effect and patient treatment preferences are more likely to be adhered to than if there was no tool in place. Specifically designed preference tools such as POLST and the LMDAD were developed and evaluated within particularly sophisticated end-of-life care models or pathways, and were highly effective at ensuring patient choices were followed through. Like all interventions which involve real-life situations it can be difficult to

unpack the intervention (preference tool) from everything else going on around it to definitively prove its effectiveness. Practitioners and policy makers wishing to use these tools should acknowledge that the evidence demonstrates that these tools work well *in particular settings* and *within particular patient-focused end-of-life care models*.

Evidence from studies set across care settings (including hospitals) or at the national level is similarly positive, but less conclusive. Once again, evidence demonstrates that when preference tools are used within a well-designed programme, or *microsystem*, for end-of-life care they are highly effective tools for recording preferences and are essential in ensuring that preferences are followed correctly.

It is telling that the body of evidence which demonstrates unequivocally that preference tools enable patient end-of-life choices to be respected are predominantly from nursing facilities/homes, community settings or in programmes where end-of-life care is well developed and care can be planned. On one level this reflects where researchers, policy makers and research funders' interests lay. However, the overall weight of evidence establishes that preference tools are effective at ensuring patients' wishes are followed through in these settings. This is as much down to the culture of care and healthcare professional buy-in of such tools as it is the tools themselves.

Evidence from the two studies which incorporated hospitals in their research settings is not as straightforward. The study by Hammes *et al* demonstrates that the preference tool (POLST) has a positive impact on patient wishes being respected and took place within the context of a highly developed end-of-life care model. Whereas the study by Teno *et al*²⁷ which found that patient wishes were followed through equally whether there was an advance directive present or not, took place within the context of a normal care

Sociologists have examined the use of medical technology in practice (from ICP documents - which are not dissimilar to preference tools - to sophisticated life-saving machinery) and theorise that if a technology is to work successfully, it needs to be developed appropriately and embedded alongside practice with buy-in from policy makers, practitioners and patients alike⁵². The findings from this review suggest that the same is true for treatment preference tools; they work best in appropriate systems.

Historically, US evidence and opinion indicated that preference tools were not effective documents for ensuring patient wishes were acted upon. This systematic review has shed light on the evidence from 2000 onwards and demonstrates that preference tools can be effective at helping to ensure patient preferences are respected. Whilst studies were conducted differently, they echoed each other's overall positive findings. This is especially true within planned end-of-life settings such as community care and nursing home setting.

However, recent evidence also suggests this can be the case in the hospital setting if the hospital is viewed as part of the same continuum of care as other more traditional end-of-life settings, and the preference tool is appropriately designed and implemented.

6.2. UK

There is some evidence to suggest that the PPC tool, or approach, ensures that patients are cared for in their preferred place. The PPC is commonly used to complement the Liverpool Care Pathway (although not exclusively) and is specifically designed for use during the last stages of life. A study by Schiff *et al*⁸ examined living wills and the Mental Capacity Act 2005 which included a partial examination of whether living wills changed treatment, but there was not enough detail published for the purposes of the review. To the best of our knowledge, no other studies examined preference tools and their effect on patient treatment wishes and matched the criteria of the review.

One of the objectives of the End of Life Care Strategy was to promote work that will:

*“... ensure that people’s individual needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible.”*¹⁹ (pg 33)

There is a shortfall in UK evidence to support this aspirational work.

7. Applying evidence from the USA to the UK

Whilst the majority of evidence in the review is from the USA, there are lessons to be learnt for the UK which could impact at the both the local and national level. Most of us won’t die peacefully in our sleep; rather we will more likely have drawn-out deaths linked to long-term conditions. Policy and practice needs to respond to this.

The End of Life Care Strategy states that:

*“...it is recommended that PCTs create locality-wide registers for people approaching the end of life, so that they can receive priority care.”*¹⁹ (pg 12)

A similar system of hospital recording of preference tools to that in the USA, or central registry of patient end-of-life treatment wishes, if developed and implemented appropriately, could be of benefit in the UK. Such a system would not only record patient preferences, and hopefully ensure they are respected, but could help to open up wider discussions around *how we die* and *how we want to die* in the UK. It is significant that one aim of the End of Life Care Strategy was to raise the profile of end-of-life care, and change attitudes to death and dying in society. This is being taken forward by the Dying Matters coalition, but it seems that more direct work by PCTs, or their successors, (such as the creation of local

registers of Advance Decisions) may be needed in order for this aim to be achieved.

Over the past ten years in the USA, there has been a flurry of locally-driven activity which has incorporated an examination of preference tools. These systems draw on local context, the needs of end-of-life patients and novel ways of framing the questions asked in preference tools.

Evidence from the USA suggests that preference tools allow patient choices to be realised when there is careful planning of where the tool fits, who the target audience is (for example, where end-of-life care can be planned), there is buy-in and associated training of healthcare professionals alongside practical measures such as storage and access to the information detailed by patients. Although the situation is changing in the UK we still have a long way to go to achieving this level of service planning and delivery. The numbers of people dying in nursing homes and homes for older people in the UK is set to rise⁵³. Policy needs to respond appropriately, with interventions to promote and respect choices. Such work should be evaluated to ensure that choices are recorded and acted on. This work should not just target this population, but it is one of particular concern.

Things are slowly changing in England and Wales. The End of Life Care Strategy was launched in 2008 which reports on the kinds of work that needs to be done to ensure patients have a good quality end of life¹⁹. This includes recommendations to develop end-of-life care plans, local end-of-life care registers, improve communication between healthcare professionals and patients and a drive to change culture around dying. More recently, the General Medical Council published guidance on treatment and care towards the end of life in 2010, which focussed on shared decision making between doctors and patients⁵⁴. We expect evaluations of these initiatives and guidelines to be published over the next few years (for example the Marie Curie Delivering Choice Programme¹⁰). Further evaluations which include an examination of whether patient preferences are recorded and respected are needed.

Evidence from the USA demonstrates that these end-of-life care objectives are achievable with appropriate development and implementation.

8. Limitations of the review

As with all research there were some limitations to this systematic review. Whilst all abstracts were read, Some studies may have been missed due to relevant information not being displayed in abstracts and hidden away in the wider study. Publication bias (whereby research which reveals negative results is not published) is an issue for any reviewer. Researchers and funding bodies may also only be interested in researching novel and interesting developments. This leaves the more mundane un-researched, with potentially useful evidence out of sight of practitioners and policy makers.

End-of-life care is a growth area with many localised projects not being evaluated or published. This appears to be especially prevalent in the UK.

9. Future research

There was a lack of relevant research literature from the UK and Europe about how preference tools are used in practice and whether they enable preferences to be followed. A large-scale study is underway in the Netherlands⁵⁵ which is taking an ecological approach to examining how preference tools work in the healthcare system. It will examine the uptake and recording of patient preferences and the impact of these tools during the patients' last days of life. In the UK, the National Institute for Health Research Service Delivery and Organisation programme is currently funding a series of projects on end-of-life care⁵⁶, none of which appear to evaluate patient treatment preference tools.

There is a clear evidence gap in the UK. Research is needed to examine how preference tools impact on end-of-life treatment decisions. We understand the legal and policy differences between the four countries of the UK, however, the systematic review search for evidence covered all four countries and we would like to prompt further research across the UK.

The following projects are suggestions which could plug the current gap in evidence:

- Ethnographic work to explore how healthcare professionals and patients interact with preference documents in a variety of settings.
- Multi-centre clinical trial to examine interventions or programmes of work which incorporate preference tools and the extent to which patient choices are acted upon.
- Evaluation of a pilot local end-of-life care registry which would incorporate patient treatment/last place of care preferences

Excluded studies

This is not a comprehensive list of excluded studies, rather studies which nearly made it into the review but were excluded for particular reasons.

Bakitas M, Ahles TA, Skalla K et al (2008) Proxy perspectives regarding end-of-life care for persons with cancer *American Cancer Society* 12(8): 1854-1861
Reasons for exclusion: Link between presence of an advance directive and decedents wishes being followed was not presented in enough detail.

Biola H, Sloane PD, Williams CS et al (2010) Preferences versus practice: life-sustaining treatments in last months of life in long-term care *Journal of American Medical Directors Association* 11(1): 42-51
Reasons for exclusion: Focus on patient characteristics and does not detail relationship or data between advance directive-type information and outcome.

Corke C, Milnes S, Orford N et al (2009) The influence of medical enduring power of attorney and advance directives on decision-making by Australian intensive care doctors *Critical care and Resuscitation* 11: 122-128
Reasons for exclusion: Not enough detail on treatment decisions made by medical personnel.

Degenholtz HB, Rhee YongJoo, Arnold RM (2004) Brief communication: The relationship between having a living will and dying in place *Annals of Internal Medicine* 141(2): 113-118
Reason for exclusion: did not contain detailed clinical information on whether the living will was consulted.

Dobbins EH (2007) End-of-life decisions - Influence of advance directives on patient care *Journal of Gerontological Nursing* 33(10): 50-56
Reasons for exclusion: not enough detail of relationship between advance directive content and treatment decisions.

Kessler DP, McClellan (2003) Advance directives and medical treatment at the end of life *Journal of Health Economics* 23: 111-127
Reasons for exclusion: Data was from 1985-1995 and did not detail whether advance decisions influenced treatment decisions.

Masuda Y, Fetters MD, Hattori A et al Physicians reports on the impact of living wills at the end of life in Japan *Journal of Medical Ethics* 29: 248-252
Reasons for exclusion: not enough data available to back up authors' claims.

Osman H, Becker MA (2003) Complexity of decision-making in a nursing home: The impact of advance directives on end-of-life care *Journal of Gerontological Social Work* 42(1): 27-40
Reasons for exclusion: not enough data available to back up authors' claims

Schiff R, Sacares P, Snook J et al (2006) Living wills and the Mental Capacity Act: a postal questionnaire survey of UK geriatricians *Age and Ageing* 35: 116-121
Reasons for exclusion: Not enough detail on treatment decisions made by medical personnel.

Schiff R, Shaw R, Raja N et al (2009) Advance end-of-life healthcare planning in an acute NHS hospital setting; development and evaluation of the Expression of Healthcare Preferences (EHP) document *Age and Ageing* 38: 81-85
Reasons for exclusion: Does not detail whether the tool impacted on end-of-life decisions

Schmidt TA, Hickman SE, Tolle SW, Brooks HS (2004) The physician orders for life-sustaining treatment program: Oregon emergency medical technicians

practical experiences and attitudes *Journal of American Geriatric Society* 52:
1430-1434

Reason for exclusion: Not enough detail on treatment decisions made by medical personnel

Seal M (2007) Patient advocacy and advance care planning in the acute hospital setting *Australian Journal of Advanced Nursing* 24(4): 29-36

Reasons for exclusion: Did not separate advance directive data from ACP enough for the purposes of the review.

Glossary of terms

CPR - Cardiopulmonary Resuscitation

DNAR . Do Not Attempt Resuscitation

DNI . Do Not Intubate

DNH . Do Not Hospitalise

GSF . Gold Standards Framework

ICP . Integrated Care Pathway

LADS - La Crosse Advance Directive Study

LCP . Liverpool Care Pathway

LMDAD - Let Me Decide Advance Directive

MCA . Mental Capacity Act

POLST - Physician Orders for Life-Sustaining Treatment

PPC . Preferred Priorities for Care

PSDA . Patient Self-Determination Act

RCT . Randomised Controlled Trial

Appendix 1

Table of results/included studies

| Author | Preference tool | Methodology | Care setting/participants | Healthcare context | Outcome (positive/neutral/negative impact and data) |
|---|--|--|--|--|--|
| Hickman <i>et al</i> (2010) ⁴¹ | Physician Orders for Life Sustaining treatment (POLST) | Retrospective observational cohort Comparison of nursing facility residents use of POLST compared to traditional practices (living will, CPR order or no documentation) n = 1, 711 deceased residents in 90 nursing facilities 817 POLST, vs. 894 non-POLST | USA Nursing facilities in three states: Oregon, Wisconsin and West Virginia 65 yrs + | Sophisticated end-of-life care model. It was initially developed to overcome the limitations of CPR orders. <i>"The POLST program is built upon a coordinated system of care across treatment settings that includes emergency services, hospitals, primary care practices, hospices and nursing facilities"</i> Program developed for people with progressive | Positive impact POLST orders restricting medical interventions were associated with less use of life-sustaining treatments. |

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| | | | | chronic illness or frailty. Included training for healthcare professionals. | |
| Hickman et al (2009) ⁴² | POLST | Review of medical records of deceased n = 275 records which contained a POLST | USA 15 POLST-using hospices in Oregon, Wisconsin and West Virginia 65+ yrs (87.1%) 19-64 yrs (12.6%) | Sophisticated end-of-life care model. It was initially developed to overcome the limitations of CPR orders. <i>“The POLST program is built upon a coordinated system of care across treatment settings that includes emergency services, hospitals, primary care practices, hospices and nursing facilities”</i> Program developed for people with | Positive impact Preferences for <i>treatment limitations</i> were respected in 98% of cases and no one received CPR, intubation, intensive care or feeding tubes. |

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| | | | | <p>progressive chronic illness or frailty.</p> <p>Included training for healthcare professionals.</p> | |
| Pekmezaris <i>et al</i> (2004) ⁴³ | Generic advance directive | Review of 93 medical records | <p>USA</p> <p>One nursing home.</p> <p>82 + yrs</p> | None stated. | <p>Positive impact</p> <p>The existence of an advance directive (indicating DNR, DNI, DNH etc.) in the patientsq records impacted on the decision to transfer the patient to the acute setting the end of life.</p> |
| Molloy <i>et al</i> (2000) ⁴⁴ | Let Me Decide Advance Directive (LMDAD) | <p>Longitudinal Randomised Control Trial.</p> <p>N = 1,292 residents in 6 nursing homes</p> <p>636 LMDAD vs. 656 control (continue to use existing policies)</p> | <p>USA</p> <p>6 nursing homes.</p> <p>Mean ages in intervention and control pairs 79.40-84.80 yrs</p> | The Let Me Decide program has been systematically implemented in nursing homes and the community and was initiated in 1988. Consistent support has been found from residents, family and healthcare | <p>Positive impact</p> <p>Nursing homes using LMDAD reported fewer hospitalisations than control nursing homes.</p> |

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| | | concerning advance directive) | | workers. Specific training for staff in the use of the LMDAD and refresher sessions throughout the study. | |
| Schamp and Tenkku (2006) ⁴⁵ | Present Directives (PD) and Advance Directives (AD) | Interventional prospective cohort - comparison pre and post Program for All-inclusive Care of the Elderly (PACE) Review of 160 medical records | USA Enrolled PACE participants (community-dwelling) 65 + yrs (83%) 64 +/- yrs (17%) | PACE is aimed at community-dwelling, frail older adults. It was launched in 1970 and in 2010 it operates in 30 States. Historically grounded in practice with ongoing training for healthcare professionals. | Positive impact Compliance with end-of-life wishes for deaths before the introduction of the Pathways Tool was 72%, compared to 96% after its implementation. |
| Degenholtz <i>et al</i> (2004) ⁴⁶ | Generic living will | Secondary analysis of data from longitudinal study of community dwelling older adults | USA 70 + yrs | None stated. | Positive impact Those with a living will were less likely to have received all life-sustaining medical treatments, more likely to have had treatments withheld and |

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|--|---|---|--|--|---|
| | | 539 cases who did not die suddenly | | | <p>more likely to had had efforts made to keep them comfortable.</p> <p>When a living will was present, people living in nursing home, the probability of in-hospital death decreased and for people living in the community the probability of an in-hospital death decreased.</p> |
| Hammes <i>et al</i> (2010) ³⁹ | POLST (also generic advance directive). | <p>Comparison of medical records/death certificates in 1995/96 and 2007/08. Part of the La Crosse Advance Directive Study (LADS) parts I and II</p> <p>LADS I: 540 cases (1995/96) LADS II: 400 cases (2007/08)</p> | <p>USA</p> <p>All healthcare organisations in La Crosse County, Wisconsin (long-term care, hospitals, home health agencies, and a county health management organisation).</p> <p>Mean age 80 yrs</p> | <p>Sophisticated end-of-life care model or <i>clinical microsystem</i>. In 1998 a state statute compliant document about end-of-life care and treatment options was produced as a guide for adults and healthcare professionals.</p> <p>In 2002 an</p> | <p>Positive impact</p> <p>Preferences regarding CPR and hospitalisation were consistent with treatment in 99% of cases.</p> |

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|---------------------------------|---------------------------|--|---|--|--|
| | | | | <p>electronic medical record which incorporated end-of-life plans was introduced.</p> <p>Training for all healthcare professionals engaging with end-of-life care.</p> | |
| Teno et al (2007) ²⁷ | Generic advance directive | <p>Interviews with bereaved family members or knowledgeable informant</p> <p>1, 587 participants</p> | <p>USA</p> <p>Nursing home, hospital and home settings</p> <p>Mean age with advance directive 79.0 yrs</p> <p>Mean age without advance directive 72.6 yrs</p> | None stated. | <p>Neutral impact</p> <p>Inconclusive as to whether the presence of an advance directive is any more effective at ensuring patient preferences are adhered to than where no official documentation is used.</p> <p>Care was reported as being inconsistent with wishes in 9.7% of those with an advance directive and in 9.5% of those with no advance directive reported.</p> |

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- ⁷ Schiff R, Shaw R, Raja N *et al* (2009) Advance end-of-life healthcare planning in an acute NHS hospital setting; development and evaluation of the Expression of Healthcare preferences (EHP) document *Age and Aging* 38: 81-85
- ⁸ Schiff R, Sacares P, Snook J, Rajkumar, Bulpitt CJ (2006) Living wills and the Mental Capacity Act: a postal questionnaire survey of UK geriatricians *Age and Aging* 35: 116-121
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