

ADVANCE CARE PLANNING IN PRIMARY CARE IN THE EAST OF ENGLAND

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If it be not now, yet it will come. The readiness is all.

Hamlet (1601) act 5, sc. 2, l. 167

ABSTRACT

Advance care planning (ACP) is a process of decision making enabling patients to establish healthcare preferences in advance of potential incapacity. Defined in statute in the Mental Capacity Act 2005, it continues to gain importance in the UK, with professional guidance advocating its use in primary care.

This qualitative study investigated ACP in UK primary care, aiming to explore current experience, ideas and views on ACP, and establish the extent to which guidance is embedded in practice. Fifteen General Practitioners and four Old Age Psychiatrists participated in individual semi-structured interviews. Themes identified were discussed in a lay focus group, before a questionnaire survey of 142 primary care practices further tested findings.

While expressing strong support for the concept, professionals displayed significant lack of knowledge about ACP and legal provisions for its use, remaining unfamiliar with guidance, and having minimal direct experience of ACP. Aware of barriers to ACP as well as potential ethical concerns, professionals acknowledged their need for training, but also stressed the importance of raising awareness of ACP amongst the general population. Feeling a need for support from other professionals in providing ACP, participants highlighted problems with availability and recognition of completed ACPs. Nevertheless, convinced of primary care's key role in ACP, they expressed commitment to its greater use.

Primary care is potentially an ideal environment to build on conceptual understanding of ACP, translating evidence, policy and guidance into practice. Despite their lack of knowledge, primary care professionals showed interest and openness to ideas regarding ACP, and were able to make relevant suggestions for improvement. These findings provide novel insight into understanding and use of ACP in primary care, with potential to form the basis for further important research as well as facilitate development of strategies to enhance implementation of patient centred ACP in this and other settings.

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INTRODUCTION

The term advance care planning (ACP) describes a process of decision making which allows individuals with capacity to establish preferences about their future healthcare in advance of a potential state of incapacity.

A concept originally developed to address public fears about modern life support technologies, advance care planning can now be seen as a key example of current commitment in medicine to patient choice and empowerment, allowing individuals to establish a valuable element of control over their future lives of which loss of capacity might otherwise rob them, with a realistic opportunity to influence their care and decisions made about that care in the future.

Beginning with the extension of a right to refuse treatment in common law to apply also to refusal of treatments in advance of future incapacity, advance care planning has since developed into a much more sophisticated medical-legal concept. It can now encompass a range of options for anticipatory decision making, from the primary ability to refuse specific medical treatments or interventions in advance, such as antibiotics or cardiopulmonary resuscitation, to the appointment of proxy decision makers to make decisions for or on behalf of the individual. Advance care planning can also allow people to articulate much broader wishes, including identification of the persons they wish to care for them and the place in which they wish to be cared for, as well as description of more general likes, dislikes and personal values, for the guidance of those caring for and making decisions about them in future.

After an extended period of development in common law followed by increasing legislative recognition of the concept in other countries, advance care planning is now established in statute in England and Wales in the Mental Capacity Act 2005, with provision for legally binding refusals of treatments in advance as well as appointment of proxy decision makers in the form of powers of attorney, and legal requirement for future decision makers to take into account more general expressions of personal wishes made in advance.

A growing body of research, largely based in the US and Canada, but also in Australia, the UK and Europe, has examined advance care planning, establishing a range of benefits of the process, identifying specific groups of patients for whom it may be of particular benefit, and investigating an array of different approaches to its use.

With the potential to provide assistance to healthcare professionals in facilitating decision making, and to improve care, particularly at the end of life, in addition to allowing important recognition of individuals' right to self determination, advance care

planning has proved a seductive concept for healthcare services and policy makers, resulting in a variety of promotional initiatives as well as the development of a number of professional guidance documents on the subject.

However support has not been universal, with advance care planning, despite its apparent attractiveness, remaining open to some criticism both practical and ethical, and with unsuccessful initiatives to establish advance care planning within patient populations resulting in recognition of a range of significant barriers to its use.

Primary care may be considered an ideal setting for the use of advance care planning, giving access to a diverse range of patients who might have the potential to benefit, as well as providing a key element of continuity of care necessary in developing sometimes complex decisions and plans over time; consequently the routine use of advance care planning in primary care has been promoted by various commentators as well as professional guidance. However, despite this, relatively little research on ACP seems to have taken place in primary care, particularly in the UK, suggesting a need for further investigation of its practice in this setting.

This thesis describes a qualitative study based in UK primary care, specifically in General Practice surgeries in the East of England, examining current practice in advance care planning and the extent to which professional guidance is embedded in practice. With discussion of some of the key factors in the development of advance care planning as a medical-legal concept, the relevant legislative framework in England and Wales will be described as well as available professional guidance. A detailed review of some of the important research evidence regarding advance care planning and consideration of significant ethical concerns will be followed by a comprehensive report of the investigation and discussion of its findings and implications.

In focusing on advance care planning in primary care, the interests of time and brevity have required some limitation in the scope of this study. Firstly, detailed consideration has been given to the legal provisions for advance care planning in England and Wales in the form of the Mental Capacity Act 2005, but it has unfortunately not been possible to cover the situation under other jurisdictions.ⁱ In addition, while it is acknowledged that advance care planning has important application in the care of patients with mental illness^(1,2) and of children with life limiting or serious illness,⁽³⁻⁵⁾ it was felt that these

ⁱ Issues regarding mental capacity and advance care planning are covered in Scotland by the Adults with Incapacity (Scotland) Act 2000, and in Northern Ireland under common law.

potentially complex situations with additional practical and ethical complications would require separate consideration and consequently they are not addressed here.ⁱⁱ

In the course of this study, a number of publications and presentations have been produced, relating to the work described in this thesis; a list of these is provided in Appendix 1 (see sections A1.1-3).

ⁱⁱ Advance care planning with children under the age of 18 as well as patients with mental illness in England and Wales may require reference to a number of pieces of related legislation including the Family Law Reform Act 1969, the Children Act 1989, and the Mental Health Act 1983 and Mental Capacity Act 2005 as amended by the Mental Health Act 2007.

CHAPTER 1

Development of the concept of advance care planning

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1.1 Central issues: development of the concept of ACP

- The latter part of the 20th century saw development of a belief, strengthened by new legal requirements regarding informed consent, that respect for individual autonomy in medical decision making was a right for patients. At the same time, the new concept of shared decision making supported the aim of involving patients in decisions about care.
- High profile legal cases and public fears regarding new life sustaining technologies led to an apparent need for a process for patients to refuse such treatment in advance, with the resultant development of the concept of living wills.
- A number of legal cases in the 1980s and 90s in the US, Canada and England clarified a common law recognition of anticipatory decision making, with refusals of treatment in advance being afforded the same weight as contemporaneous decisions.
- Experience of living wills subsequently led to recognition of their limitations, resulting in development of the concept of proxy or surrogate decision makers, who could be appointed by individuals to make decisions on their behalf in the case of incapacity.
- Following common law recognition of the concept, many US states were quick to develop legislation putting living wills and healthcare proxies on firmer statutory footing.
- Several articles of the European Convention on Human Rights have potential impact on ACP, while the Convention on Human Rights and Biomedicine has specific requirements regarding recognition of previously expressed wishes in healthcare.
- As a result, European countries are increasingly developing their own statutory provisions for ACP, with the UK having put in place legislation in 2007 with the Mental Capacity Act 2005, which covers refusal of specific medical treatments in advance as well as appointment of healthcare proxies with the ability to make decisions on behalf of a person lacking capacity.

1.2 Background to the concept

For some 2000 years, the practice of medicine had remained fixed in a model of beneficence, or action by doctors to benefit their patients.⁽⁶⁾ Under this model, which can arguably be traced back to the Hippocratic tradition, doctors made decisions with a paternalistic authority, with little meaningful role for patients in decision making, in a relationship based on trust and obedience.⁽⁶⁾ The 20th century, however, saw significant changes taking place in the approach to medical decision making.⁽⁷⁾

In 1859 in *On Liberty*, the English philosopher John Stuart Mill, placing emphasis on the importance of individuals' wants and preferences, argued that individuals had a right to liberty or self determination as long as this did not harm others. Fifty five years later, the American case of *Schloendorff v Society of New York Hospital*ⁱ illustrated the possible application of the concept of self determination to patients:

'Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.'

Subsequent cases (*Harnish v Children's Hospital Medical Center*,ⁱⁱ *Canterbury v Spence*ⁱⁱⁱ) clarified the development of a new American common law doctrine of informed consent, which although arguably as much to do with increasing malpractice litigation as patients' rights,⁽⁸⁾ ushered in a new model of decision making in medicine, involving greater provision of information to patients as part of the process.

Alongside this, broader social changes were taking place: a civil rights movement, a general increase in discussion about ethical and moral issues in medicine and research, and philosophical debate taking the form of a novel field of bioethics, centred particularly on interest in respect of the rights and values of individuals. A logical result of this social discourse was development of the belief that not only was respect for individual autonomy in terms of informed consent to medical treatment now a legal requirement in some areas, it was also a universal moral right of patients as autonomous agents.⁽⁷⁾ Consequently, the latter part of the twentieth century started to see a substantial shift in focus away from a paternalistic or beneficent model of medicine,

ⁱ 211 N.Y. 125, 105 N.E. 92 (1914). Please note, a number of legal cases are mentioned throughout this chapter. These are listed, with full references, in the table of cases at the beginning of this thesis.

ⁱⁱ 387 Mass. 152, 439 N.E.2d 240 (1982).

ⁱⁱⁱ 464 F.2d 772 (D.C. Cir. 1972).

towards a belief in patient self determination and respect for individuals' autonomy in decision making as essential features of ethical and effective medical practice.

Continued promotion of rights and choices of patients as core elements to provision of healthcare was also associated with a move towards the practice of more patient centred medical care. This is reflected in the development of the concept of shared decision making, increasingly believed to be an ideal model of medical treatment decision making,(9,10) with the ultimate aim of patients being involved in every aspect and decision about their care.

Seen on the background of these changes, a significant difficulty is apparent in the form of patients who lack decision making capacity.(11) With patients now necessarily involved in all decisions, there was a need to reconsider the approach to making decisions on behalf of patients who lacked the ability to make decisions for themselves. The idea of doctors making all the decisions about the care of a patient, for example, with advanced dementia, or with significant cognitive impairment following a stroke, or unconscious following a road traffic accident, would not sit well with new and strongly held beliefs about the paramount importance of individual autonomy.

In addition, at around the same time came the additional complication of substantial developments in medical technologies. With modern medicine now having the ability to continue to support life, despite very serious injury or illness, in patients who no longer had any ability to communicate or make decisions about their care, many began to fear the possibility of 'entrapment' in these new life support technologies,(12,13) in what could be seen as a protracted, artificial and undignified process of dying.(14)

High profile cases in the courts and the media heightened public awareness of these issues and the difficulties faced regarding decision making about seriously ill, unconscious and incapacitated patients, with a need becoming apparent for a process by which patients could avoid unwanted medical treatments or interventions when they no longer had the ability to refuse them.

In 1969 the Chicago attorney and human rights campaigner Luis Kutner proposed his solution to situations such as when '*a patient does not desire to be kept in a state of indefinite vegetated animation*':(15)

'...the individual, while fully in control of his faculties and his ability to express himself, indicate[s] to what extent he would consent to treatment. The document indicating such consent may be referred to as a living will.'

Based on longstanding statutes governing testamentary wills which determine distribution of property after a person's death, Kutner thought out his proposal in considerable detail. He recommended that such documents could only be made by someone able to consent to treatment, and that no one should be able to make a living will for someone else. The document should be witnessed and signed, and held by the patient as well as a relative, physician or lawyer. It could be revoked at any time, until the patient was 'comatose', with subsequent actions of the person also potentially affecting whether the document was considered binding. When the time came for it to be used, a special hospital committee should be established to determine the person's intent in writing the document and that the situation envisaged had been reached. Finally, such a document could not be used as a means to direct a doctor to act affirmatively to end the patient's life, although it could require the doctor to '*act passively by inaction*'.

As will be seen, these proposals describe with remarkable accuracy the essential elements of the current legal approaches developed by many countries, including the UK, to deal with anticipatory decision making or advance care planning (ACP) in healthcare.

1.3 ACP at common law

Statutory recognition of processes for anticipatory decision making by patients concerning their medical care was not immediately forthcoming following proposals for living wills such as those of Kutner. However, over time the courts in various jurisdictions, including England and Wales, came to acknowledge a right of competent patients to refuse treatments, including life sustaining treatments, and to make such refusals in advance in the expectation that they would subsequently be treated as binding on medical professionals. Arguably this process began in 1976 with the New Jersey case *In Re Quinlan*,^{iv} before a cluster of cases in the US, Canada and England in the 1980s and 90s shed further light on the area.

1.3.1 *A right to refuse treatment*

Karen Ann Quinlan had collapsed in 1975 and subsequently remained in an unconscious and unresponsive condition following ingestion of a combination of

^{iv} 70 N.J. 10, 355 A.2d 647 (1976).

benzodiazepines and alcohol at a party. Kept alive on a ventilator, her father and the hospital where she was a patient sought a declaration by the court to allow them to withdraw treatment without fear of criminal prosecution.

At appeal, the New Jersey court, in ruling to allow this to take place, recognized a constitutional right, pursuant to the right to privacy, to refuse unwanted bodily interventions, which could include requesting the termination of life sustaining interventions already started. In addition, those following a patient's expressed wishes in this way would not be subject to any criminal or civil liability.

In England and Wales, in the case of *Sidaway v Board of Governors of the Bethlem Royal Hospital*,^v the court described the existence of a right to 'self determination' that was,

'...no more and no less than the right of a patient to determine for himself whether he will or will not accept the doctor's advice...'

This right of patients to make their own decisions should, the judge argued, be seen as *'...a basic human right protected by the common law'*, and a doctor treating a patient who had exercised the right to refuse that treatment would be guilty of the civil wrong of trespass to the person as well as the criminal offence of assault.

The same autonomous right to determine what should be done with one's own body was said in the Canadian case of *Malette v Shulman*^{vi} to be *'a fundamental right in our society.'* This was *'long recognized in common law'* being protected by the tort of battery, and would extend to apply to consent to or refusal of medical treatment.

F v West Berkshire Area Health Authority,^{vii} confirmed the existence in English law of a general principle that medical treatment of an adult patient is unlawful unless that patient has given valid consent to that treatment, with the judge in *Re T*,^{viii} going further to state:

'This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent.'

^v [1985] AC 871.

^{vi} (1990), 72 O.R. (2d) 417 (Ont. C.A.).

^{vii} [1990] 2 AC 1.

^{viii} [1993] Fam 95.

In *Airedale NHS Trust v Bland*,^{ix} the hospital and family of Antony Bland, a patient in a persistent vegetative state following injuries sustained during the Hillsborough disaster, sought a similar declaration from the court to that in *Quinlan*, that it would be lawful to withdraw all life sustaining treatment including artificial ventilation, nutrition and hydration. Referring to *Nancy B v Hotel Dieu de Quebec*,^x where the patient, who had Guillain-Barre syndrome, wished her doctors to be able to turn off the ventilator which kept her alive, it was confirmed that a doctor acts lawfully in respecting a patient's wishes in refusal of life sustaining treatment, even where this may result in the patient's death.

1.3.2 Refusals made in advance

The judgement in *Bland* also made it clear that patients' refusals of treatment in advance, or 'advance directives', should be given the same degree of respect as those made contemporaneously:

'Moreover the same principle applies where the patient's refusal to give his consent has been expressed at an earlier date, before he became unconscious or otherwise incapable of communicating it...'

This issue had previously been addressed in *Shulman* where a patient who was a Jehovah's Witness was given a blood transfusion in hospital while unconscious, despite having a card on her person, made known to the medical team, stating her refusal to accept treatment with blood products. Although the transfusion almost certainly saved her life, the Canadian court ruled that,

'She was entitled to reject in advance of an emergency a medical procedure inimical to her religious values.'

Approving the judgment in that patients' prior refusals of treatment should be binding on health professionals and that doctors acting against them would be acting unlawfully, the English court in *Re T* qualified this, placing three conditions on the binding nature of such refusals: first the patient must have had the capacity to make the decision at the time the refusal of treatment was made; second, the refusal must really be that of the patient, made without undue outside influence; third, the 'scope and basis' of the decision must fit the present circumstances.

^{ix} [1993] AC 789.

^x (1992), 86 DLR (4th) 385 (Que Sup Ct).

The first condition, decision making capacity, will be discussed below. In ensuring that the decision was made without undue outside influence, the question to be asked is (according to *Re T*):

‘Does the patient really mean what he says or is he merely saying it for a quiet life, to satisfy someone else or because the advice and persuasion to which he has been subjected is such that he can no longer think and decide for himself? In other words, is it a decision expressed in form only, not in reality?’

‘Scope and basis’, meanwhile, refers to necessity that the patient fully intended the decision to apply to this particular situation and understood its likely impact. If the decision was based on false assumptions, or was of limited scope that did not include the current situation, it would not be binding.

Following the precedent set in *Re T*, a number of later cases examined advance directives refusing medical treatments and made it clear that they should be scrutinised with great care, especially when relating to life sustaining treatments, and that where there was doubt concerning the validity of such a decision, English courts would usually rule in favour of preservation of life. In *HE v A Hospital NHS Trust*,^{xi} the judge explained that,

‘The continuing validity and applicability of the advance directive must be clearly established by convincing and inherently reliable evidence.’

And furthermore,

‘The longer the time which has elapsed since an advance directive was made, and the greater the apparent changes in the patient’s circumstances since then, the more doubt there is likely to be as to its continuing validity and applicability.’

However, decisions made in advance to refuse life sustaining treatments that are clearly valid and applicable will be respected. In *Re AK*,^{xii} a patient with motor neurone disease requested that his ventilator should be turned off two weeks after he lost the ability to communicate. Ruling in his favour, the judge stated,

‘The expressions of AK’s decision are recent and are made not on any hypothetical basis but in the fullest possible knowledge of impending reality.’

^{xi} [2003] EWHC 1017 (Fam).

^{xii} [2001] 2 FCR 35.

1.3.3 *Substitute decision makers and healthcare proxies*

In *Quinlan* the American court gave authority to the patient's father, as 'guardian of her person and property', in consultation with other members of the family, to make the decision to refuse medical treatment requiring the withdrawal of artificial ventilation. This, the court argued, amounted to allowing the family and guardian to exercise her right to privacy on her behalf, using '*their best judgement... as to whether she would exercise it in these circumstances.*'

The limitations of written living wills in terms of interpretation, particularly with regard to applicability, with limited scope and inflexibility, led many American states to pursue the concept of healthcare proxies as an alternative way of anticipatory decision making.⁽¹⁴⁾ Based on common law and statutory provisions for powers of attorney and legal guardianship, these allowed an alternative personal decision maker, or surrogate for the incapacitated patient, to make decisions on their behalf.

English common law was not to recognize this concept in so far as it does not allow anyone, even the court, to give consent on behalf of an incapacitated adult patient. However, although not able to make decisions on the patient's behalf, healthcare proxies could present evidence of a person's prior wishes, and if that evidence were strong enough to meet the requirements set out in *Re T*, those wishes would be considered binding.

As will be discussed later (see section 2.3.3), provisions now exist, under the Mental Capacity Act 2005, for proxy decision makers in the form of Lasting Powers of Attorney, allowing the appointment of a person who can in fact make decisions about medical treatment on the patient's behalf.

1.3.4 *Limitations on ACP*

Common law decisions also placed two important limitations on the use of anticipatory decision making.⁽¹³⁾ Advance directives could not be used to justify any action that could not be authorized by a patient with capacity. Therefore, it would never be lawful for a doctor to provide treatment or carry out any action with intention or purpose of ending a patient's life. As was seen in the case of *R v Cox*,^{xiii} such actions would lead to charges of murder. Secondly patients have no right to demand particular treatments either contemporaneously or in an anticipatory request, and such demands are not

^{xiii} (1992) 12 BMLR 38.

binding on doctors; nothing can require a doctor to give a treatment that he does not believe is in the patient's best interests.

1.3.5 *Capacity to consent to treatment and the best interests test*

Valid consent to treatment, and equally valid refusal of treatment, requires the patient to have the legal capacity to make that decision and to be aware in broad terms of the nature and purpose of the proposed treatment (*Chatterton v Gerson*).^{xiv}

In English law, every adult is assumed to have capacity, but certain circumstances may lead this to be rebutted (*Re T*):

'...a small minority of the population lack the necessary mental capacity due to mental illness or retarded development. This is a permanent or at least a long-term state. Others who would normally have that capacity may be deprived of it or have it reduced by reason of temporary factors, such as unconsciousness or confusion or other effects of shock, severe fatigue, pain or drugs being used in their treatment.'

It has been suggested⁽¹³⁾ that there are three approaches to patients' capacity to make decisions: a 'function' test, where the actual ability to make the decision is assessed, a 'status' test, where capacity is determined by the patient's status, such as age, and an 'outcome' test where the patient's decision is compared with that which a 'competent' person might have made.

The approach of the English courts to capacity shows a clear preference for a 'function' test.⁽¹⁶⁾ While all adults are assumed to have capacity, and similarly all children under the age of 16 are assumed to lack capacity to make decisions, this initial 'status' approach is qualified. Where there is any doubt, the actual decision making abilities will always then be assessed using a functional approach.

Such a test was proposed in *Re C*,^{xv} and took place in three stages:

1. Can the patient comprehend and retain the treatment information?
2. Is he able to believe this information?
3. Can he weigh this information in the balance in order to come to a choice?

This test of capacity was confirmed by the court of appeal in *Re MB*^{xvi} and remained the test for capacity in England and Wales until it ultimately formed the basis for a statutory test for capacity in the Mental Capacity Act 2005.

^{xiv} [1981] QB 432.

^{xv} [1994] 1 WLR 290.

Re C concerned a patient in Broadmoor hospital with chronic paranoid schizophrenia. The court's decision to recognize his capacity to refuse surgery to amputate his gangrenous leg, despite a high chance of his death as a result of this refusal, on the basis of application of this test, also demonstrated two important points. Firstly there was no place for an 'outcome' test for capacity in English law; C's decision was clearly unwise and arguably irrational, but this was not relevant to his capacity. Secondly, status of the patient, specifically mental illness, likewise had no impact on the judgement of capacity; despite suffering from delusions as a result of his schizophrenia C still retained the capacity to refuse his surgery.

In providing a test for decision making capacity, the courts also recognized that there would be cases where patients failed to demonstrate capacity and yet medical treatment was still required. For those situations, where patients were unable to consent to treatment, and had made no prior indication of their wishes, the course of action to be pursued should be decided in their 'best interests' as defined in *F v West Berkshire HA*:

'A doctor can lawfully operate on, or give other treatment to, adult patients who are incapable, for one reason or another, of consenting to his doing so, provided that the operation or other treatment is in the best interests of such patients. The operation or other treatment will be in their best interests if, but only if, it is carried out in order to save their lives, or to ensure improvement or prevent deterioration in their physical or mental health.'

1.4 ACP legislation

Following the case of *Quinlan*, some American states were relatively quick to legislate, with a legal mechanism for anticipatory decision making first introduced in the form of living wills in the California Natural Death Act 1976. Over time all fifty states and the District of Columbia came to recognize patients' right to indicate their wishes about healthcare in advance, with most having statutory support for both living wills and healthcare proxies.⁽¹⁷⁾ In 1990 the US Federal Government enacted the Patient Self Determination Act, intended to support state laws by imposing obligations on hospitals and other healthcare facilities to ask patients about and provide information on advance directives.

^{xvi} [1997] 2 FLR 426

Similar processes occurred in many other countries, with common law recognition of anticipatory decisions in the courts followed by some form of legislation for their use. In European countries this process has taken place more slowly than in the US, arguably being particularly driven only around the beginning of the twenty first century by European legislation relating to human rights.

1.4.1 *Human rights legislation in Europe and ACP*

A number of articles in the European Convention on Human Rights have the potential to impact on anticipatory decision making:(16) Article 2 (the right to life), Article 3 (the right not to be subjected to inhuman or degrading treatment), Article 5 (the right to liberty), Article 8 (respect for private and family life), Article 9 (respect for religious views).

More specifically relating to this area are some of the provisions of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology, (also known as the Convention on Human Rights and Biomedicine), which came into force in 1999. Detailing requirements regarding consent to and refusal of treatment (Article 5), it offers protection for patients unable to consent to treatment (Article 6) and makes respect for patients' previous wishes in healthcare decisions a necessity in signatory states:

Article 9 – previously expressed wishes

The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.

1.4.2 *European domestic legislation on ACP*

Despite Europe wide legislation and agreement in the form of the European Convention on Human Rights and Biomedicine, the wording of the statement about previously expressed wishes allows relatively wide interpretation, and consequently a very varied legal situation exists in European countries with regard to anticipatory decision making

for healthcare. Four groups of countries have been described in relation to their legislation in this area:^{xvii}(18)

- 1) Those with specific laws that make patients' anticipatory decisions about healthcare binding (UK, Austria, Spain, Hungary, Belgium, The Netherlands, Finland, Germany)
- 2) Those where specific laws exist but where these decisions are not binding, having only an advisory role (France);
- 3) Those where there are no specific laws regarding anticipatory decision making, but which do have existing plans to introduce such legislation (Switzerland, Italy);
- 4) Those where no specific laws in this area exist, and which do not have any plans to introduce them in the near future (Norway, Portugal, Greece, Serbia, Slovakia, Bulgaria, Lithuania, Turkey).

In the UK, specific legislation has existed since 2007 when the Mental Capacity Act 2005 came into effect. This gives detailed provision for adults with capacity to make anticipatory decisions about their healthcare, including refusal of specific treatments in advance and appointment of a healthcare proxy with the ability to make decisions for the person should they lose capacity. These provisions are discussed in the following chapter.

^{xvii} For further information on country specific practices and legislation regarding ACP, see the collaboratory on advance directives set up by Simon-Lorda, P et al. Available from: <http://www.voluntadesanticipadas.com>

CHAPTER 2

Advance care planning under the Mental Capacity Act 2005

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2.1 Central issues: ACP under the MCA 2005

- The Mental Capacity Act 2005 (MCA 2005) provides a framework for decision making on behalf of individuals lacking capacity, including specific provision for ACP.
- The MCA 2005 recognizes three outcomes of ACP:
 - Advance statement of wishes: a non binding expression of wishes for future care which can later provide a guide for best interests decisions.
 - Advance decision to refuse treatment: a legally binding refusal of treatment which can include refusal of life sustaining treatment.
 - Lasting Power of Attorney (LPA) for health and welfare: appointment of someone to make decisions on a person's behalf in the event of incapacity.
- For most decisions there are no statutory requirements for documentation of advance statements or advance decisions to refuse treatment, although some evidence of existence will be necessary for any advance refusal to be binding.
- Advance decisions to refuse life sustaining treatments must be in writing, signed and witnessed, and state specifically that they are to apply even if the person's life is at risk.
- LPAs require completion of a statutory form signed by both parties. A certificate must be provided confirming the understanding and absence of coercion. Where intended to apply to life sustaining treatments, this must be specifically stated. LPAs must be registered with the Office of the Public Guardian before they can be used.
- Assessment of mental capacity to participate in ACP should be carried out using the statutory (MCA 2005) test for capacity, and should be judged with regard to the specific decision or decisions involved.
- A number of safeguards exist against potential abuses of ACP under the MCA 2005, and decisions made under the Act can be revised, changed or revoked at any time that the person has capacity to do so.

2.2 Introduction

Despite considerable developments in the common law, a need was evident for legislative reform to provide a clear legal structure in the area of mental capacity and decision making for people who did not have the ability to make decisions for themselves.

Consequently, following an extensively researched Law Commission report on Mental Incapacity in 1995, a draft Mental Incapacity Bill was published by the Government in 2003. After much further consultation and a number of amendments, the resulting Mental Capacity Act gained Royal Assent in 2005, coming into force on 1st October 2007.

Providing a comprehensive framework for decision making on behalf of individuals lacking capacity, the Mental Capacity Act 2005 (MCA 2005) gives statutory recognition to the process of ACP in the UK, as well as specific description of the terms ‘incapacity’ (MCA 2005 s.2), ‘inability to make decisions’ (MCA 2005 s.3), and ‘best interests’ (MCA 2005 s.4). It also establishes a new Court of Protection with jurisdiction to decide on these issues, as well as giving responsibility to the Office of the Public Guardian for administration and overseeing certain aspects of ACP including registration of powers of attorney.

The following pages describe the provisions made in the MCA 2005 relevant to ACP, including requirements involved in making and documenting ACP decisions, and assessment of capacity to participate in the process.ⁱ Further details on the basic structure of the MCA 2005 as well as its descriptions of incapacity and best interests are included in Appendix 2.

2.3 Advance care planning under the Mental Capacity Act 2005

The MCA 2005 does not use the term ‘advance care planning’, but the concept is clearly contained in the statute, which reinforces the common law principle that competent individuals have the right to consent to or refuse any treatment, and refusals

ⁱ Acknowledging the complexity of some aspects of the provisions of the MCA 2005 described, BH had discussions with Officers of both the Court of Protection and the Office of the Public Guardian to clarify the practical working of this legislation, particularly where relating to safeguards in the use of ACP. The information in the following pages therefore is derived both from these discussions as well as the referenced material including the MCA 2005 itself and relevant guidance.

of treatment made in advance by such individuals will be binding (Re T,ⁱⁱ Re Cⁱⁱⁱ). The Act essentially establishes three possible routes for anticipatory decision making or ACP, each of which takes effect only if and when the person concerned loses capacity:^{iv}

2.3.1 *Advance statement of wishes (MCA 2005, s.4(6)(a))*

While they are not defined specifically, the MCA 2005 undoubtedly recognizes the existence of statements made of wishes for future care, distinct from refusals of treatment and powers of attorney, and the use of such statements is discussed in the MCA 2005 Code of Practice (MCA 2005 Code of Practice 5.40-5.45). Although they will not be legally binding on healthcare professionals, the Act expects these statements to be considered as being of particular importance when assessing a patient's 'best interests'.

Advance statements allow people to set out their wishes for future care, aiming to provide a guide for healthcare professionals and others involved in looking after them as to what is likely to be in their best interests. As such, advance statements may cover any aspect of care and may be quite specific in their description of preferences, for example stating the particular place where the person would like to be cared for, naming people whom the person would like to be involved in that care, or describing types or manners of treatment that the person would like to receive. However they can also be much more general, perhaps giving an overall view of the person's likes and dislikes in order to enable readers of the statement to gain some understanding of the personal values of the individual.

Some people wish to make requests for particular treatments or care in advance and it is recognized that such requests are of importance. However, while they should be taken into account by healthcare professionals, and treated with the same consideration that such requests made contemporaneously by someone with capacity would be (MCA 2005 Code of Practice 5.34), they will never be legally binding and the MCA code of practice takes particular care to explain that these cannot be used to demand the use of treatments, including life sustaining treatments, deemed inappropriate by the clinician

ⁱⁱ [1993] Fam 95.

ⁱⁱⁱ [1994] 1 WLR 290.

^{iv} As will be discussed later (see section 2.3.3.1), Lasting Powers of Attorney for Property and Affairs are an exception to this rule as they will usually be able to be used as soon as they are registered.

and contrary to the patient's best interests. This is in accordance with existing common law that doctors are under no legal or ethical obligation to provide treatment in these circumstances (*R (Burke) v General Medical Council*).^v

2.3.2 *Advance decision to refuse treatment (MCA 2005, ss.24-26)*

An advance decision to refuse treatment is a legally binding refusal of a particular treatment made in advance of future incapacity and can include refusal of life sustaining treatment. In making provision for these, the MCA 2005 recognizes the common law principle that people have a right to refuse any treatment, and that such refusals made in advance by people with capacity should be binding. Therefore, advance decisions must be valid and applicable to the circumstances in which they are to be used but, if they are, should be treated in the same way as a contemporaneous refusal of treatment by a person with capacity, with healthcare professionals potentially facing criminal prosecution or civil liability if they fail to follow the decision.

An example of an advance decision to refuse treatment might be where a person states that they would not wish to be given treatment with antibiotics should they develop a chest infection when already suffering from end stage cardiac failure, with details provided of the specific treatment, the condition and circumstances where it is to be refused.

In line with common law, any medical treatment can be refused, including potentially life saving or sustaining treatments and artificial nutrition and hydration without which the person is likely to die. As will be seen, advance decisions to refuse treatment must always be as specific as possible, and this is especially so when refusing life sustaining treatments, where clearly there is no room for error in interpretation of the person's wishes; consequently certain requirements apply in terms of documentation and witnessing of the such decisions.

Patients can only refuse medical treatments. While artificial nutrition and hydration are recognized as medical treatments and as such can be refused, it is not possible to make advance refusal of 'basic or essential care' necessary to keep a person comfortable, including warmth, shelter, actions to keep the person clean, and the offer of food or water by mouth (MCA 2005 s.5, Code of Practice 9.28). Nor is it possible to make any refusal or request that would involve healthcare professionals being expected to do

^v [2005] EWCA 1003.

anything that would be against the law; the Act takes care to make clear that its provisions do not change in any way the law relating to murder, manslaughter or assisted suicide (MCA 2005 s.62).

2.3.3 Lasting Powers of Attorney (MCA 2005, ss.9-14, Sch.1)

The provisions of the MCA 2005 for Lasting Powers of Attorney (LPA) allow the appointment of someone with legal authority to make decisions on a person's behalf. The power to make decisions acquired by the holder of an LPA or 'donee' is strictly subject to the principles of the MCA 2005 and the best interests criteria; all actions and decisions of the attorney must be made in the best interest of the 'donor'.

Replacing the previously existing Enduring Powers of Attorney which gave the chosen 'attorney' authority to make decisions about the person's property and financial affairs, LPAs under the MCA 2005 can be used to appoint a person or persons to make decisions about both property and financial affairs and or personal welfare issues including healthcare. While this will often be the same person, it is possible to appoint several attorneys who may act jointly or with different specified responsibilities.

Recognizing the significant powers of decision making given in LPAs, and the major responsibility of holding one, the Act specifies a number of formalities associated with creation of a Lasting Power of Attorney, and all LPAs must be registered with the Office of the Public Guardian before they can be used.

2.3.3.1 Lasting Power of Attorney for property and financial affairs

Providing broadly similar powers to Enduring Powers of Attorney (EPA) under the previous system, Lasting Powers of Attorney for property and financial affairs give the holder the authority to make decisions on behalf of the donor in the specific area of his personal property and financial affairs. This authority is only available once the relevant formalities have been completed and the LPA registered with the Office of the Public Guardian. However, once this has been done, the donee will have the ability to make decisions whether or not the donor retains capacity. This does not of course do anything to remove decision making power from the donor, who will continue to be able to make any decisions for which he retains capacity, but the donee will also have the power to

make these decisions, as well as decisions in any areas where the donor now lacks capacity.^{vi}

2.3.3.2 *Lasting Power of Attorney for health and welfare*

Under the new provisions of the MCA 2005, a person given a ‘health and welfare LPA’ can make decisions both about someone’s medical treatment and personal welfare issues such as day to day care and where to live. The powers given to an attorney may also include the ability to make decisions regarding life sustaining treatment but only if this is expressly stated and documented at the time of making the LPA. In the same way as with advance decisions to refuse treatment and advance statements of wishes, an LPA cannot be used to demand treatment that is not necessary or appropriate, or to do anything that would otherwise be against the law.

In contrast to LPAs for property and financial affairs, even once registered, LPAs for health and welfare give the holder power to make decisions only in areas where the donor currently lacks capacity; this sits perhaps more logically with the other provisions for ACP in being aimed more clearly at decisions affecting a person’s care and treatment following loss of capacity.

2.4 Making and documenting ACPs

Although for most kinds of decisions there is no statutory requirement for formal documentation of ACP discussions, in order to ensure that details of people’s wishes are known and available at the time when they are needed, it will usually be important that they are appropriately recorded. This may be for example in the person’s healthcare record, or as a signed document held by one or more persons such as their General Practitioner, Solicitor or next of kin, or as a hand held document carried at all times by the person in case of emergency.

^{vi} This reflects the historical development of powers of attorney, which were originally deemed to expire on incapacity of the donor, with Enduring Powers of Attorney being established specifically to allow these powers to continue to be used after donors lost the ability to make decisions. Interestingly, since the introduction of the MCA 2005, EPAs may only be used if registered with the Office of the Public Guardian, which for EPAs can be done only when the attorney considers that the donor has lost capacity.

2.4.1 *Advance statements and advance decisions to refuse treatment*

There are no formality requirements for advance statements of wishes under the MCA 2005, which are recognized simply as one of a number of ways to inform best interest decisions. The MCA 2005 Code of Practice advises that a person's views relevant to 'best interests'^{vii} assessment may be expressed verbally or through behaviour or habits, or recorded in writing or in other ways such as home video or audiotapes. However the Act does place special emphasis on the importance of written statements made by people before loss of capacity, and this is likely to be the most effective way of ensuring future availability of these wishes in order that they be taken into account by those assessing best interests.

Advance decisions to refuse treatment can be made only by people over the age of 18, who have capacity to make the decision in question. In order for an advance decision to refuse treatment to be legally binding, some evidence of its existence will always be necessary.^(19,20) Although there is no statutory form available, it is likely that a written record would provide the strongest evidence, although audio or video recording might also be used. A variety of specimen forms have been produced and are available online, including from NHS bodies such as the NHS End of Life Care Programme and the Gold Standards Framework; some hospital trusts have also produced their own versions.^{viii} The MCA 2005 Code of Practice advises that where people give advance decisions to refuse treatment verbally, these should be wherever possible documented in their healthcare record.

In addition, the decision must be 'valid' and 'applicable' in the current circumstances. In order to be valid, it must be possible to establish that the person has not withdrawn the decision while he still had capacity, made a subsequent LPA conferring responsibility for this decision, or done anything else which is '*clearly inconsistent with the advance decision remaining his fixed decision*'. A decision will not be applicable if

^{vii} A brief explanation of the 'best interests' principle and its use under the MCA 2005 is provided in Appendix 2 (see section A2.1.2).

^{viii} BH was part of an advisory committee for St Helena Hospice in Colchester and Colchester Hospital University NHS Foundation Trust devising an Advance Care Planning document for use in the local area; a copy of this document is provided in Appendix 3. Included as an example of a typical document, this is not in any way claimed to be an ideal model for discussion and recording of ACPs; indeed, readers of later chapters (see particularly section 4.6) will readily appreciate the limitations of this particular document in terms of length, clarity, and accessibility to those of different cultural backgrounds and educational levels or literacy skills.

the treatment now in question is not that specified in the decision, any circumstances specified are absent, or if there are 'reasonable grounds' to suspect that circumstances have changed in a way that the person did not anticipate but which would have affected the way he made the decision. Clearly these criteria will be difficult to meet unless the decision states very specifically the circumstances in which it is to apply, giving details of the treatment to be refused and in what medical condition. Evidence of recent review of the decision would be likely to help in ensuring validity, and care will be needed to avoid any unintended conflict between LPAs and advance decisions.

Where a decision refers to refusal of life sustaining treatment, the greater weight and significance of this refusal means that the MCA 2005 requires further criteria to be met. Such a decision must state specifically that it is to apply to the treatment even if the person's life is at risk and, although there is no statutory form, it must be recorded in writing, signed by the patient or someone at his direction, and witnessed.

No formal process exists for registration of either advance statements of wishes or advance refusals of treatment and there is usually no charge for making them. Some people may decide to seek legal advice on making and recording these decisions and in this case they are likely to be charged a fee especially if any documents are drawn up. However professional guidance suggests that ACP should be viewed by healthcare professionals as a part of normal good practice, and as such should not attract a fee.^(19,21)

2.4.2 *Lasting Powers of Attorney*

Perhaps unsurprisingly given the considerable decision making authority it gives to the holder, appointing someone with Lasting Power of Attorney is the most formalised element of ACP under the MCA 2005, with a number of specific requirements detailed in the Act. Donors of LPAs must be over 18 years and have capacity to make the LPA. In contrast to advance statements and Advance Decisions to Refuse Treatment, there are statutory forms available for LPAs, both for property and financial affairs and for health and welfare, and these must be completed, including prescribed information on the nature and effect of the LPA (Lasting Powers of Attorney, Enduring Powers of Attorney and Public Guardian (Amendment) Regulations 2009 (SI 2009/1884)).^{ix} In addition to

^{ix} This form can be found on the website of the Office of the Public Guardian. Available from:

naming the person or persons they wish to be given the power of attorney, these forms allow donors also to name up to five other ‘people to be told’, who will be informed of the existence and registration of the LPA and then have the ability to raise any concerns they may have about the LPA with the Court of Protection.

In the same way as with advance refusals of treatment, if an LPA for health and welfare is intended also to apply to life sustaining treatment, this must be specifically acknowledged and the LPA form must expressly state that it is intended to confer authority to the attorney to consent to or refuse treatments of this type (MCA 2005 s.11(8)(a)). Where this has been done, the attorney must still of course always act in the person’s best interests, and the Act particularly stresses that the attorney must not in any way be motivated by a desire to bring about the person’s death (MCA Code of Practice 7.30-7.31)

The donor of the LPA must then read the completed document and sign to confirm that it is to apply when he loses capacity, and similarly the recipient or recipients of the LPA must sign to accept their responsibilities, with regard to which they should refer to the MCA 2005 which lists the ‘duties’ of attorneys (MCA 2005 Code of Practice 7.52-7.68).

Finally, unlike advance statements of wishes and advance decisions to refuse treatment, LPAs must be registered with the Office of the Public Guardian before they can be used to make any decisions. This registration incurs a fee, which is currently £110.^x While it is possible to complete an LPA without legal advice, many people do wish to consult a solicitor for advice and may be charged up to £900 for this service.^{xi} While registration is essential if the LPA is to be used, it is also advisable that information on any LPA be kept in the healthcare record with details of the attorney and scope of authority.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/211171/LPA114_health_and_welfare_LPA.pdf

^x Information regarding registration of LPAs and the costs involved can be found on the website of the Office of the Public Guardian. Available from:

<https://www.gov.uk/government/publications/power-of-attorney-fees>

^{xi} Moon S. Is £900 a fair price for a power of attorney? This is Money, 2009. Available from: http://www.thisismoney.co.uk/tax/ask-an-expert/article.html?in_article_id=480716&in_page_id=112

2.5 Mental capacity to participate in ACP

Any advance care planning requires the person involved to have the mental capacity to make the relevant decisions in order to participate in the process. While the Act requires that people should be assumed to have capacity unless there are reasonable grounds to doubt it, it is possible that many of those for whom ACP seems particularly appropriate may also be of questionable capacity⁽²²⁾.

Where this is in question, assessment of capacity to participate in ACP should be carried out using the statutory test provided by the MCA 2005, and ideally the assessment recorded with the ACP. Capacity will as usual have to be judged with regard to the particular decision to be made rather than for the process as a whole;^{xii} an ACP may be made up of a number of different decisions and the patient may have capacity for any or all of them.

2.5.1 *Advance statements and advance decisions*

The capacity required to make an advance statement of wishes or an advance decision to refuse treatment is the same as that needed to make the equivalent decision contemporaneously.⁽¹⁹⁾ As with any decision, the person will need broadly to understand the treatment options and implications of the decision, as well as being aware that circumstances may change and medical advances occur.

Since advance statements of wishes may give information about personal beliefs and values rather than describing specific decisions, they may not fit easily within the MCA 2005 test framework. Furthermore, such statements of values, intended to inform best interests decisions rather than be followed directly, might arguably require a lower level of capacity than for example a specific advance refusal of treatment.

2.5.2 *Lasting Powers of Attorney*

In the same way as with advance decisions to refuse treatment, the MCA 2005 requires that a person wishing to make a lasting power of attorney (LPA) has sufficient capacity, and the statutory test will apply. The person would therefore be expected to be able to understand the foreseeable consequences of making or not making the LPA or of making it in different terms or appointing a different person as attorney.

^{xii} This may not necessarily be the case for LPAs, as will be discussed below (see section 2.5.2).

Interestingly, capacity to make an LPA may not necessarily equate with the capacity required to make the decisions potentially involved in subsequent use of the power of attorney. In the case of *Re K, Re F*,^{xiii} it was held that someone could have the capacity to make an EPA despite at the time lacking the capacity to manage his property and affairs. Commentators suggest⁽²⁰⁾ that it is likely that this ruling will also apply in the case of LPAs under the MCA 2005.

In addition to assessment of capacity, the Act also requires completion of a 'certificate of understanding' as part of the LPA documentation. Completed by an appropriate independent third party, such as a GP or solicitor, this must confirm the following:

- a) In their opinion, the person appointing the LPA understands its purpose and scope.
- b) No fraud or coercion was used in persuading the person to make the LPA.
- c) There is nothing else to stop an LPA being appointed.

2.6 Safeguards in the use of ACP

In providing a framework for decision making on behalf of incapacitated people, the MCA 2005 aims to protect and support such people: those dealing with them or providing their care are expected to act in accordance with the 'principles' of the Act,^{xiv} which seek to promote the ability of people to make decisions for themselves where possible, whilst ensuring that where decisions must be made on their behalf, these are made in their best interests and in such a way as to limit any restriction of their rights and freedom of action.

Nevertheless there would seem to be significant potential for abuse of ACP, arguably particularly where rights of decision making over property and financial matters are concerned; the ability of LPAs for property and financial affairs to be used as soon as they are registered, while the donor retains capacity, might raise specific concerns about coercion of capacitate but vulnerable persons. Perhaps acknowledging that the appointment of people with power of attorney is an area of ACP especially susceptible to coercion or wrongful use, the MCA 2005 includes a number of provisions intended to act as safeguards.

^{xiii} [1988] 1 All ER 358.

^{xiv} See Appendix 2, section A2.1 for a full list of the principles of the MCA 2005.

Firstly, donors have the ability to name more than one person to hold the power of attorney and to indicate whether these people are to act jointly or severally (MCA 2005 s.10). In a similar requirement to that for advance decisions to refuse treatment, if a donor wishes their LPA to give the person the ability to refuse life sustaining treatment on their behalf, this must be specifically stated on the statutory form.

In addition, donors have a degree of flexibility in what they allow attorneys to make decisions on and how they go about the decision making process (MCA 2005 s.9(4)(b)). A section of the statutory form allows the donor to list ‘restrictions’ on the LPA, which are binding on attorneys, as well as ‘conditions’, which are advisory in nature. Potentially this allows donors to place LPAs for property and financial affairs on similar footing to those for health and welfare, by making a restriction on the use of the LPA to the effect that it must only be used in circumstances where the person has lost capacity.^{xv}

Donors are also able to name a number of ‘people to be told’ (MCA 2005 Sch.1.2(1)(c)(i)) who will be informed of the registration of the LPA and given the opportunity to raise objections with the Court of Protection if they have any concerns.^{xvi} Objections can either be on ‘factual grounds’, for example if the person believes that the donor or the attorney has died, or the attorney lacks the mental capacity to be an attorney, or on ‘other grounds’, such as a belief that the donor lacked capacity when the LPA was made, there was fraud or coercion in the making of the LPA or the attorney is failing to act in the best interests of the donor. Surprisingly, however, people who have not been ‘named’, while they are still able to raise objections, are subject to a £400 court fee in doing so; this would apply for example to GPs wishing to raise concerns

^{xv} A guidance note on the website for the Office of the Public Guardian describes this as a ‘typical, useful’ restriction to place on an LPA. However it was unclear following discussion with a representative of the Office to what extent this occurs in practice. The relevant guidance note is available from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/245569/LPA112_Property_financial_affairs_guidance.pdf

^{xvi} An Officer of the Court of Protection stated that this does occur in practice, with people regularly coming to the Court with objections around the time of registration of LPAs, although naming of individuals will very much depend on existing family structures.

about the LPAs of their patients, unless the patients in question had named them in the document.^{xvii}

Finally, the MCA 2005 gives powers to the Office of the Public Guardian to investigate potential abuse of LPAs (MCA 2005 s.58), which include the ability to request financial accounts from holders of LPAs. However, in practice, attorneys are not supervised or policed in any formal way;^{xviii} indeed, commentators(20) have highlighted the fact that while these powers for investigation exist, with no routine scrutiny taking place to identify potential abuses, it is not at all clear how such issues would come to the attention of the relevant authority. Financial disincentive in the form of the court fee for third party objections would seem to make identification and investigation of potential abuse even less likely.

2.7 Review, change and revocation of ACP

The MCA 2005 allows people to change their minds about decisions at any time that they still have capacity to do so, revoking or changing any advance statement, advance decision to refuse treatment (MCA 2005 s.24(3-5)), or LPA (MCA 2005 s.13(2)).

Arguably, advance decisions that have been reviewed recently are more likely to be found to be valid and applicable and consequently regular review while people retain capacity, as well as review at the time of any significant developments or changes in personal circumstances, is encouraged in the MCA 2005 Code of Practice (9.29-9.30). People can also revoke these decisions at any time they have capacity, with no formal process required. Changes to advance decisions can be made verbally or in writing, although it will always be advisable for a record to be kept as evidence of the change.

Similarly, LPAs can be changed or revoked at any stage, before or after registration, while the donor retains the capacity to do so. Revocation of an LPA requires completion

^{xvii} Discussion with a representative of the Office of the Public Guardian confirmed that this is the case. It was suggested, however, that two other approaches might be possible for those with concerns about an LPA. Firstly, where concerns exist regarding a vulnerable person, they could be raised with Social Services, who it was suggested have perhaps greater powers for investigation than the Court of Protection or Office of the Public Guardian. In addition, if the donor has already lost capacity, any third party may raise concerns about safeguarding of that person with the Office of the Public Guardian without incurring a fee.

^{xviii} This contrasts with the situation for 'deputies', sometimes appointed by the Court of Protection to have a similar role to donees of powers of attorney where no LPA has been made; here, where the person's assets exceed £19000, an annual financial report must be submitted to the Court, which may lead to further investigation.

of a 'deed of revocation' by the donor, which should be sent to the Office of the Public Guardian.^{xix} Due to the complex formalities and registration process for LPAs, changes would usually require the making and registering of a new LPA. Finally, donees of LPAs are under no obligation to accept the responsibility of taking on power of attorney, and can 'disclaim' the LPA at any time by completion of a specified form.^{xx}

^{xix} An example is given on the website of the Office of the Public Guardian. Available from: <https://www.gov.uk/power-of-attorney/cancel-or-end-a-lasting-power-of-attorney>

^{xx} This form can also be found on the website of the Office of the Public Guardian.

Available from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/208544/lpa005.pdf

CHAPTER 3

Existing research evidence on advance care planning

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3.1 Central issues: existing research evidence on ACP

- Healthcare professionals, patients and families share positive attitudes towards ACP, which is considered important in terms of autonomy and control over future care and believed to enhance communication and facilitate decision making.
- Some have concerns, in particular that patients may lack sufficient understanding of ACPs and may change their minds when faced with situations in reality.
- Patients may have specific views on ACP, with greater comfort in discussion of ACP than anticipated by professionals, as well as specific goals, with decisions strongly influenced by family relationships and a desire to relieve burdens.
- Knowledge and experience of ACP amongst both professionals and the public tends to be low, with professionals often lacking familiarity with relevant guidance.
- Despite earlier lack of success, a number of studies have been effective in engaging people in ACP. These have demonstrated:
 - ACPs are respected resulting in treatment consistent with patients' wishes.
 - ACP can also increase family and patient satisfaction with care, and reduce stress, anxiety and depression in surviving relatives.
 - ACP may also have benefit in reducing use of healthcare resources.
- ACP may be appropriate in a number of situations, including end of life and elderly care, and life limiting conditions. It may also be particularly suitable in dementia.
- ACP can be initiated in a variety of settings, with evidence suggesting that primary care may be an especially suitable environment for its use.
- Numerous practical, psychological and social barriers exist to the effective use of ACP. Studies have proposed various ways by which these may be overcome, relating particularly to approach to ACP, family involvement, documentation and education.

3.2 Introduction

Current healthcare policy and professional guidance on ACP is supported by a growing body of research evidence investigating a wide range of related themes for the use of ACP in a variety of settings. In particular, a number of studies have looked at attitudes of healthcare professionals and patients towards ACP; others have investigated the success of ACP in terms of uptake and achievement of its aims in establishing and respecting patients' wishes about future care, as well as identifying barriers and facilitators to the use of ACP.

This chapter describes the findings of a narrative review of literature providing evidence regarding ACP. Articles were initially sought through searches of the online databases MEDLINE, EMBASE and PsycINFO, followed by examination of abstracts to identify relevant articles which were then obtained in full text, with further citation searching from key articles subsequently.

These studies tend to use a variety of different terms; wherever the meaning is clearly equivalent, they will be discussed here using the term ACP. There are however some articles where different terminology or elements of ACP such as advance decisions or powers of attorney are particularly relevant to the findings, in which case the terms used in the original study are used.

3.3 Attitudes, views and beliefs

A variety of studies have explored attitudes, views and beliefs about ACP among healthcare professionals and patients as well as families, both in terms of theoretical discussion of ACP and participants' experiences of use of ACP.

One large Canadian survey(23) of family physicians identified 86% (n=643) of participants as favouring the use of ACP, while another study in the US(24) suggested 79% of physicians (n=790) were supportive of ACP, with only 1.5% expressing a negative attitude towards the concept. Similar support has been demonstrated amongst healthcare professionals in European studies, with one survey of Finnish physicians(25) (n=448) finding 92% to have a positive attitude towards ACP, although results of one study of Scottish General Practitioners(26) suggested more cautious support with 44% (n=517) reporting that they were in favour of ACP.

Patients also show strongly positive attitudes, with 81% (n=97) of cancer patients in one survey(27) intending to write an ACP, and 83% (n=100) wanting to know more about ACP. Healthy controls were also interested in ACP, with 90% (n=100) wanting to know

more, and 60% (n=99) intending to write one. These data supported previous findings amongst elderly medical inpatients,(28) 72% (n=76) of whom expressed interest in making an ACP. Meanwhile, a qualitative study of residential nursing home residents suggested support for ACP amongst families,(29) with family members speaking positively about the concept when interviewed.

3.3.1 *Autonomy and control*

Widespread agreement exists on the strength and importance of ACP allowing patients to express their autonomy in decision making with regard to their future treatment.(23,29,30) Recognition of patients' autonomy was established in one study(31) as the prime determining factor for positive attitudes to ACP amongst physicians, nurses, healthcare administrators and patients. Meanwhile, patients with HIV(32) felt that ACP was particularly important in allowing them to achieve a sense of control, providing a framework which helped them organise their thoughts about the future and establish and articulate their preferences.

A strong conviction exists among health professionals(24) that it is important for patients to be able to influence their treatment should they lose capacity, with a high degree of value placed on the potential of ACP to safeguard autonomy,(30) and 89% (n=790) of physicians considering ACP to be an effective way of doing this.(24) There is also recognition(33) of the ability of ACP to facilitate offering patients choice in terms of future care.

ACP is believed by healthcare professionals to have the potential to confer a feeling of peace of mind for patients,(30) particularly in terms of their ability to control their future care and avoid unwanted treatment in the event of loss of capacity or ability to communicate;(23) physicians of various specialties have shown over 80% agreement with this belief (n=790 and 629).(24,34) Professionals also associate ACP with an increase in patients' comfort with the dying process, through recognition of dying and approval of the way of dying.(35)

Patients seem to hold largely similar views,(36) describing maintaining control as one of their main goals of ACP, with such control usually meaning limiting treatments in order to avoid prolonging the dying process. Many also perceive ACP as a means of preparing not only for potential loss of capacity but also for death, with the process of ACP providing them with a feeling of security about the future.(36)

3.3.2 *Communication and decision making*

Evidence exists in the literature of a general belief that ACP can facilitate communication and decision making, often in considerably broader terms than simply with regard to patients making decisions directly relating to ACP. Clinicians state that they feel more comfortable treating patients with ACPs, and that these assist in the provision of good clinical care, allowing professionals to make more confident decisions,(35) with existence of a clear indication of a patient's wishes considered likely to make decision making much easier for doctors;(37) 78% (n=84) of physicians with experience of ACP felt that decisions had been made easier by this.(34)

In the palliative care setting,(33) Community Nurses have expressed the view that ACP has the ability to open up dialogue about end of life care, establishing a therapeutic relationship, facilitating a shift of emphasis from curative to palliative care. Physicians seem to have had similar experience, with 61% (n=448) in one study agreeing that ACP can act as an 'ice breaker' in discussing end of life treatment.(25) Meanwhile, Geriatricians describe ACP in their experience as making end of life discussions easier and helping to reach a consensus about care and provide clarity for non medical staff and relatives.(34)

Other professionals have found that ACP resulted in an opening up of communication among patients, families and caregivers, leading to discussions which could prove very useful in future decision making,(35) and helping to establish more trusting relationships (83%, n=790).(24) ACP may also have the ability to enhance communication between healthcare professionals and families, allowing them to work more closely, and helping to build relationships and resolve conflicts or silence.(33) In particular, where disagreements existed between patients and families about how aggressive treatment should be, ACP helped lead to agreement,(35) with family and physician guided towards a pathway of care of the patient's wishes; 72% (n=634) of family physicians in one study felt that ACP resulted in reduction in family discord over decisions to withdraw treatment.(23) Consequently,(38) General Practitioners felt that use of ACP, where legally binding, might help to mitigate their fear of litigation, with there being less likelihood of disagreement with families when such ACPs were in place.

It has been suggested that ACP may also be of help to family members themselves, giving them peace of mind at the time the ACP is implemented(30) and comfort in bereavement,(33,38) where they have been more aware of and involved in respecting

the wishes of the patient. In one study there was a strong belief amongst physicians (90%, n=790) that families experience less sense of guilt about 'not doing everything' when an ACP was in existence.(24)

In this context, ACP, in the form of advance directives regarding future treatment, has sometimes been seen as of particular benefit from the point of view of patients in terms of relieving family members of the responsibility of having to make difficult decisions,(31) with reducing the burden of decision making on family being one of the most commonly expressed reasons for elderly medical inpatients participating in ACP (30%, n=74).(28)

3.3.3 *Effects on action of healthcare professionals*

Professionals and patients support a belief that ACP will have an effect on care and the action of healthcare professionals, with the majority of patients (approximately 80%, n=100) as well as healthy controls, nurses and physicians in one study(27) believing that ACP would influence quality of treatment received in terms of pain, type of treatment and duration of suffering. For physicians, experience of ACP influencing care in practice has been strongly associated with positive attitudes to ACP,(24) suggesting a belief in beneficial impact on care.

Of physicians with experience of use of ACP in clinical situations,(34) 39% (n=280) had changed treatment as a result of an ACP, with a positive effect on care in more than half of these cases, enabling physicians to treat less aggressively or less actively in respect of patients' wishes. In another study,(25) physicians considered it to be important to respect ACPs, which they felt, in their limited experience, to have a moderate to major effect on the planning of treatment.

One study has revealed a view of healthcare professionals that ACP could help prevent situations where relatives feel unable to 'let go', protecting patients from what was seen as over intervention driven by relatives, and allowing professionals to implement appropriate changes or withdrawal of treatments.(30) Physicians also believe that the presence of ACP may make them less likely to practise defensive medicine(24,26), and make it psychologically easier to withdraw futile treatment.(26)

However, clearly not all healthcare professionals are prepared to follow ACPs in all clinical situations, with 44% (n=126) in one study(23) stating that they always followed ACPs, but 55% (n=128) saying that they had at some point refused to follow one. Reasons for this included: the family disagreed with the ACP, the wording was not

believed to fit the clinical situation, the patient was not terminally ill, and the preferences were not thought to have been fully understood by the patient or were out of date.

3.3.4 *Reservations, criticism and negative beliefs*

While findings in studies of attitudes to ACP have tended to reveal mostly positive views, both professionals and patients have frequently expressed some degree of concern or reservations about certain aspects of ACP.

The potential for ACP to change the balance of responsibility in decision making from doctor to patient might lead to particular concerns for some clinicians.(37) Evidence exists for a belief that discussion of ACP and end of life care may prove too upsetting or depressing for patients, who might be unable to deal with the relevant issues emotionally.(39,40) In addition, there may be some perception that patients often lack the ability to understand the issues involved in ACP.

Many healthcare professionals feel that an important part of their professional role is advising on future illness, prognosis and treatment, including end of life care, and that they have competence in these areas, developed through years of training and experience, which gives them the ability to make complex decisions about the end of life.(24,37) However, some feel unsure about the ability of patients, who are likely to lack this knowledge and experience, to grasp the complexity of medical decisions recorded in ACPs;(37) 83% (n=474) of Geriatricians(34) were concerned that patients might complete ACPs with insufficient understanding of their meaning.

In this context, clinicians have worried about the 'informedness' of patients in the process,(30) believing that individuals might have misconceptions about the nature of their illness, especially regarding prognosis, and that they might also misunderstand the benefits and roles of certain types of intervention in the palliation of symptoms; patients' views might conceivably change significantly if they had sufficient information about the situation or options available.(35)

In fact, a small but significant number of clinicians (14%, n=108) in one study(34) felt that ACP had actually had a negative impact on care, with ACPs appearing late in patients' admission, and resulting in withdrawal of interventions including artificial nutrition in a way that was seen as inappropriate by the clinicians. There was also a fear that patients might change their mind about the issues decided in an ACP when they actually faced the real situation (85%, n=485).

This concern has been shared by participants in a number of other studies,(24) with professionals highlighting the point that preferences made in advance may not equate with those of unwell patients.(30) However, where illness resulted in irreversible incapacity, there was some feeling that it was better to have decisions informed by patients' previous wishes, even if they were potentially inaccurate.

The literature also suggests the existence of concern about the possibility of misuse, with one study demonstrating support for beliefs that ACP might be used by relatives to insist on cessation of therapy despite favourable prognosis, that patients might be coerced into completing ACPs, and that physicians might use ACPs as the basis for decisions without consideration of the prognosis and type of illness.(27) These fears were shared by patients, healthy controls, nursing staff and physicians, with physicians showing the greatest level of concern for each possibility.

While ACP may be of benefit in reducing the burden of decision making on relatives,(28) this would be of significant concern if ACP is made for the 'wrong reasons', such as depression or a fear of being a burden on relatives or carers.(25) This would be particularly worrying if patients were able to request active measures to end life.(35) Suggestions that ACP might be misused have also been connected by some with the question of healthcare service funding,(26) with a small group of General Practitioners (17%, n=517) believing that pressure would be put on patients to make ACPs in order to justify rationing of healthcare.ⁱ

Healthcare professionals in several studies have expressed concerns about the clarity of instructions in some ACPs,(35) arguing that they are often too vague to be of use, although being too specific may also result in difficulty in using ACP; general statements about withholding and withdrawing treatment were felt to be unhelpful by 48% (n=517) of General Practitioners.(26)

Some professionals(35) fear that ACPs may conflict with clinical judgment, preventing them from exercising their judgment where decisions have already been made by the patient or are made by an appointed surrogate decision maker. ACPs can be seen as imposing additional control that is not useful, that interferes with medical action, and calls clinicians' judgment into question;(31) others however have referred to a

ⁱ Please note, concerns regarding prediction of future wishes, coercion, euthanasia and rationing are discussed further in Chapter 4 (see sections 4.3, 4.6 and 4.7).

temptation to transfer responsibility for difficult decisions to the patient by the use of ACP.(25)

One study with Community Nurses,(33) showed a level of criticism of General Practitioners in particular, with a belief that they felt discomfort in discussing ACP and feared raising end of life issues too soon; a perception of reluctance amongst clinicians to disengage from an 'active' curative model was shared by some patients in another study.(41) Furthermore, what was seen as increasing bureaucracy in the use of ACP was felt to lead to an inappropriately 'one size fits all' approach, although it was also believed that problems with documentation, storage and retrieval of ACPs could be a major issue, leading to medical staff pursuing the least risky course of action where there was a lack of documented evidence of wishes.

Finally, professionals have raised specific concerns about one element of ACP, Lasting Powers of Attorney for personal welfare,(34) suggesting that the use of these instruments might result in too great a burden of responsibility for holders of these powers, particularly where there might be a high potential for conflicts of interests either emotional, financial, or in terms of the individuals' health beliefs.

3.3.5 Particular and differing views of patients

While patients share views on ACP with healthcare professionals in a number of areas, several studies have suggested attitudes held by patients which add significantly to what might be seen as the established 'clinical' view of ACP.

The purpose of ACP for many patients seemed to be to prepare for death, rather than incapacity,(36) with a striking willingness to participate in ACP and enthusiasm in particular for discussion of end of life preferences,(41) contrasting with the concerns expressed by professionals about ACP upsetting patients.(39,40) In fact, some patients see ACP as a way to help face and accept the prospect of death, with confronting and planning death being important steps in coping with this.(32)

Participation in ACP and patients decisions were found to be strongly influenced by their concern for others, with a major goal of the process being to relieve the burden on loved ones, giving them 'permission' in ACP to withdraw treatments.(36) As well as helping reduce the burden of decision making on loved ones, ACP could also be of value in altering the emotional burden on family and friends of a person's dying;(32) in opening up communication and enabling loved ones to participate in the experience of patients, it was felt that ACP could actually help to strengthen relationships.

3.4 Knowledge and experience

Despite support for ACP in terms of positive attitudes to the concept, studies have largely demonstrated low levels of knowledge and experience of ACP in both healthcare professionals and patients.

One interview study with elderly people in the UK (carried out before statutory provision for ACP was introduced in the MCA 2005)(28) found that 82% (n=74) had never heard of living wills, advance directives or advance statements, with most of those who had thinking they applied only to financial arrangements after death. While a more recent study in Germany seemed to suggest greater public awareness, with 74% of patients being aware of the existence of advance directives (n=100),(27) still less than half of patients and less than a third of healthy controls were aware of legal provisions for proxy decision makers. A recent survey in Australia suggests that while increasing numbers of patients may be aware of the concept of ACP, few understand it in terms of articulating what it means.(42)

Furthermore, both the general public and healthcare providers may be confused about matters concerning end of life care,(43) and it has been suggested(31) that while healthcare professionals may be more familiar with the existence of ACP than patients and the general public, they still show a degree of confusion about the status of ACP documents.

Awareness of ACP amongst healthcare professionals in older studies is reported as relatively low, with 63% (n=117) of General Practitioners in one Australian study reported as knowing of legal provision for living wills.(44) Knowledge about ACP has been similarly found to be lacking, with only 49% (n=214) of General Practitioners in one UK study (carried out prior to the introduction of the MCA 2005) knowing that advance directives carried legal force, and many were confused about other aspects of their legal status such as whether treatment refused by patients in advance must be withheld.(45)

However, while most healthcare professionals might now be expected to have heard of ACP, with 98% (n=100) in one more recent study having heard of advance directives for example,(27) experience of its use seems to remain relatively limited: 45% (n=448) of physicians had been in a situation where ACP had been active during the process of decision making,(25) and 56% (n=811) of Geriatricians had cared for patients with living wills, of whom 62% had cared for them at the time the will came into effect, with few ever having helped a patient to make one (6%, n=809).(34)

Where professionals in this last study had discussed ACP with patients, they sought advice from various sources including British Medical Association guidance. However, previous studies would suggest a lack of familiarity with professional guidance on ACP,(26) with some not aware of important relevant guidance at all.(46)

More recently,(33) Community Nurses showed awareness of ACP from local teaching on end of life care and ACP as well as use of ACP tools such as the Gold Standards Framework, but most still felt a lack of confidence in the components of ACP, with some perceiving it as a specific set of paperwork and exhibiting confusion about how ACP interacts with the 'day to day care planning' that they saw as their normal role. Consequently participants in this study highlighted a need for further training in ACP, and in particular communication training specific to ACP. Several other previous studies have commented on the education of healthcare professionals on ACP, identifying a need for training at both undergraduate and postgraduate levels.(47,48)

3.5 Evidence for use of ACP in practice

Despite the admirable intentions of ACP as a concept, disappointing results of some studies have led to significant criticisms of the process. Some commentators(12) have raised fundamental concerns regarding the concept of ACP as based on flawed assumptions.ⁱⁱ In addition, it has been argued specifically, based mainly on the results of one large US trial of an ACP intervention, that despite interventions to promote their use, patients do not participate in ACP, if they do, it makes no difference to their care, and use of ACP has no impact on use of healthcare resources.(49)

3.5.1 *The SUPPORT study*

In 1995 the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), published its report.(50) A large observational study of 4301 patients, followed by a clinical trial of 4804 hospitalised seriously ill patients over two years, this investigated an intervention to improve ACP in terms of reducing the frequency of mechanically supported, painful or prolonged dying. A trained nurse facilitator for ACP provided detailed information on prognosis and outcomes of treatment to both physicians and patients, aiming to elicit patients' preferences, improve understanding of conditions, improve pain control, and facilitate ACP and

ⁱⁱ These issues are discussed further in Chapter 4, section 4.3.

communication. Demonstrating existing shortcomings in communication and both process and decision making in end of life care, the study looked at a variety of outcomes including patient-physician communication, incidence and timing of documented resuscitation preferences, physicians' knowledge of their patients' preferences, number of days in an intensive care unit, on mechanical ventilation or in a comatose state, and reduction in hospital resource use. However, the investigators reported no change in any of these as a result of their intervention.

Further analysis of SUPPORT data in a series of publications later established that few patients had advance directives (21%) and that this did not change post intervention.(51) Where advance directives were completed and placed in medical records, they often did not affect decision making,(52) and documented advance directives did not result in reduction in use of hospital resources.(53)

3.5.2 *Participation in ACP*

Following the disappointing findings of SUPPORT, researchers took note of the lessons learned from studies into attitudes and beliefs of patients about ACP, particularly those looking at the process from the patient's perspective. As a result, a number of studies have since demonstrated much more success with participation in and completion of ACP following educational or promotional interventions.

In one Canadian study set in six nursing homes,(54) in an intervention called *Let Me Decide*, local hospital and nursing home staff, residents and their families were educated about ACP, and nurses trained as facilitators discussed treatment choices with competent residents and the families of incompetent residents with the help of an advance directive document. Systematic implementation of this process resulted in 49% (n=177) of competent residents and 78% of families (n=350) completing directives. Meanwhile, researchers in the US retrospectively compared prevalence of advance directives before and after a two year intervention called *Respecting Choices*.(55) Here, community based educational and promotional efforts to address cultural reluctance to discuss death and dying were combined with a facilitated discussion between patient and healthcare professional. Discussions were carried out by non physicians, and aimed to help patients and families discuss wishes for end of life, focusing on clearly defining these wishes and documenting them to be available for future reference. Of 540 deceased patients studied, prevalence of written advance directives was 85%, with 95% of these being documented in the patient's medical record, contradicting predictions that

prevalence of ACPs would be unlikely to exceed that of testamentary wills.(56) Most had been completed significantly before the time of death (median = 1.2 years).

A later survey of 700 elderly individuals in New York suggested changing prevalence of ACP use, with 35% stating that they had carried out ACP in the form of appointment of a proxy decision maker for healthcare.(57) This study linked increased ACP use with a number of factors including having an established primary care physician, experience of mechanical ventilation, knowledge about the process of ACP, and having a physician willing to initiate discussion of ACP.

More recently, another US study looked at a larger data set of 3746 patients taken from the Health and Retirement Study, a survey of US adults.(58) Of 999 deceased patients who had needed medical decisions to be made at the end of life and lacked decision making capacity, 68% had an advance directive, showing a substantial increase in use of ACP in the general population since the findings of SUPPORT fifteen years previously, with the authors suggesting that this implied patients find advance directives to be 'familiar, available and acceptable' and that it might be expected that they, their families and healthcare providers also believe them to have value.

3.5.3 *Benefits and effectiveness*

SUPPORT demonstrated lack of any effect of ACP on a variety of factors relating to end of life care in hospital patients, findings that were consistent with a previous much smaller study of nursing home residents,(59) where the effectiveness of advance directives was found to be limited by inattention of professionals to them. While the treatment that patients received at the end of life was consistent with their previously expressed wishes most of the time, the presence of a written directive did not affect this. However subsequent work suggested that rather than being ignored,(60) ACPs were often deemed not applicable; many referred to care at the very end of life, in terms of withdrawal of treatment, and families and physicians often did not recognize the patient as having reached this point.

In addition, several subsequent studies seem to show that ACP does in fact make a significant difference to end of life care, with the *Respecting Choices* study(55) concluding that treatment decisions made in advance appeared to be consistently followed in making end of life decisions, while the much larger investigation of patients from the Health and Retirement Study,(58) found that those who had made advance directives received care that was strongly associated with their preferences.

Furthermore, there now exists evidence for benefits of ACP wider than simply resulting in care according with patients' wishes. Drawing on lessons learned from previous studies,(49) a prospective study of 309 medical inpatients was recently carried out in Australia.(61) Participants were randomly assigned either to usual care or an ACP intervention called *Respecting Patient Choices*, based on the US *Respecting Choices* model, where non medical facilitators, in a coordinated approach with doctors, assisted patients in reflecting on their goals, values and beliefs, and discussed and documented their future choices about healthcare. End of life wishes were known and respected in 86% (n=29) of those who died in the intervention group compared with 30% (n=27) of the control group; overall, in those whose wishes were known they were respected in 92% of cases (n=36). In addition, however, ACP was associated with increased patient and family satisfaction with care, as well as reduced stress, anxiety and depression in surviving relatives. It was concluded by the investigators that advance care planning carried out properly with trained staff improves end of life care by enabling patients' wishes to be determined, documented and respected; key elements to the success of this programme were felt to be the use of trained facilitators, patient centred discussions, involvement of family, correctly filed documentation, and systematic education of doctors.

This study noted a finding of increased satisfaction amongst patients who had received the ACP intervention, who were more satisfied with overall care in the hospital, the information provided, being listened to, and being involved in decision making. This reinforces suggestions in other studies that there are benefits to be gained from ACP before any decisions made as part of the process come into effect, that is, more immediate effects on patients before loss of capacity. For example, investigation of patients with end stage renal disease,(62) demonstrated that the ACP process had the ability to positively enhance hope amongst this group. Enabling patients to develop a sense of control over their future care, reducing anxieties about the future and about death, and strengthening relationships with family and other loved ones(32,36) might all contribute to increased satisfaction of patients with care at an early stage as a result of involvement in the process of ACP.

3.5.4 *Financial considerations*

While SUPPORT failed to establish any impact of ACP use on healthcare costs, the question of whether this process may be able to reduce utilization of health service

resources has remained an important one, particularly relating to end of life care given established knowledge that most of patients' lifetime healthcare costs are incurred in the final years of life.(63) A number of subsequent studies have examined this further, with more positive results.

The *Let Me Decide* study(54) suggested that advance directives reduced health services utilisation including hospitalisation, with fewer hospitalisations per nursing home resident over an 18 month period, and significantly lower overall healthcare costs for residents in intervention homes compared with controls.

Another study in Australian nursing homes with 1344 residential aged care beds,(64) carried out systematic education of nursing home residents, their families, staff and General Practitioners about the terminal nature of dementia, the process of ACP, and Hospital In The Home (HITH), a programme offering intravenous antibiotics and blood transfusions administered by a hospital outreach team. This education was combined with subsequent ACP discussions with patients and relatives based on the *Let Me Decide* programme. The researchers found that this joint intervention resulted in reduced ambulance use and reduced hospital admissions. The study even claimed reduced mortality as a result of the intervention based on unchanging mortality in the intervention group compared with an expected increasing trend in mortality in controls.

Recently, two groups of researchers have examined the economic impact of ACP specifically. Applying the results of previous studies to data obtained from the *Respecting Patient Choices* programme of ACP implementation in Australia, estimated hospital savings were calculated in terms of Occupied Bed Days saved.(65) Researchers concluded that an ACP has the potential to reduce terminal hospital admission by nine days, which when extrapolated across four proposed projects to facilitate ACP in a variety of community and acute care settings was suggested could equate to potential cost savings of AUS \$5.6 million, with an investment of AUS \$200,000. Another group in Germany,(66) carried out a systematic review of studies assessing cost efficiency of ACP programmes. Examining seven studies, they pointed out that ACP interventions were often poorly defined and difficult to distinguish in terms of sole impact of ACP, with interventions often including a variety of elements in an approach to end of life care of which ACP was just part. With preliminary data suggesting that potential savings with ACP might outweigh costs, the researchers nevertheless stressed the need for further systematic evaluation of the economic impact of ACP programmes, while

adding a note of caution regarding the potential political and ethical impact of such research.

The possibility that the existence of potential cost savings might act as a driver for ACP or be seen as an aim of the process may raise significant ethical concerns (see section 4.6), and of course if ACP can be considered to provide significant benefits to patients, higher costs should arguably still be acceptable. However, reduction in use of healthcare services in times of financial difficulty, considered as a secondary outcome of ACP promoting wise use of resources, can clearly be seen as desirable.

3.5.5 ACP in specific medical conditions

Developed largely as a means to establish decisions and preferences about treatments at the end of life, there has been a longstanding association of ACP with end of life care and palliative care with improvement in this area being a key aim of the process. Presumably aiming to capture those for whom decisions about end of life care may be of greater priority, studies have focused on elderly patients^(57,67,68) as well as those with significant life limiting conditions, such as Chronic Obstructive Pulmonary Disease,⁽⁶⁹⁾ Human Immunodeficiency Virus,⁽³²⁾ end stage renal disease,⁽⁶²⁾ cancer⁽⁷⁰⁾ and heart failure.⁽⁷¹⁾ Indeed, recognizing that patients with different illnesses may have different and specific needs in ACP, there is a move towards development of disease specific interventions for ACP in various chronic medical conditions,⁽⁷²⁾ as well as considering those who might not normally be thought of as appropriate for ACP, but for whom consideration of future wishes may in fact be of great interest:⁽⁷³⁾ patients facing high risk surgery, for example, or those who have suffered one potentially life threatening or significant medical event, such as cerebrovascular or cardiac events, and may be at risk of more. It is also clear that ACP will be of relevance to many patients with mental illness,⁽¹⁾ with one recent study demonstrating interest of patients in discussing and establishing preferences about future medical treatment, and highlighting the feasibility and acceptability of a standardized approach to ACP in this group.

One condition that has aroused particular interest with regard to ACP has been dementia. A condition where sufferers are highly likely to lose capacity to make treatment decisions in the future, it has been recognized that patients with dementia are an important potential target group for ACP,⁽⁷⁴⁾ with focus on early diagnosis of dementia,⁽⁷⁵⁾ arguably increasing interest in this area.

Commentators highlight a particular lack of ACP use in dementia however, perhaps related to a failure to view dementia as a terminal condition,(76) with patients with dementia significantly less likely to have ACP than those with cancer, while being more likely to suffer burdensome investigations;(77) particular barriers have been identified to ACP in dementia,(74) including referral to other professionals for discussions, and a belief that patients with dementia lack the capacity to make the relevant decisions. Researchers stress the need to discuss ACP at an early stage in the diagnosis, while patients retain the capacity to participate in the process;(78) in fact there is evidence to suggest that a significant proportion of patients with early dementia still retain capacity for ACP.(79) Two recent reviews have looked at the existing evidence for use of ACP in patients with cognitive impairment and dementia,(80,81) pointing to a need for further research to establish ACP as an evidence based part of routine dementia care, and suggesting that approaching ACP in this condition in the nursing home environment was likely to be too late for most patients.

3.5.6 Setting of ACP: use in primary care

Studies have investigated ACP in a variety of settings, though they have largely focused on the hospital inpatient(61) or outpatient environment,(82) or in the community, particularly in residential and nursing care.(64,83) However, evidence suggesting that patients wish ACP to be initiated by their doctor, early, and at a time of relative wellness,(84) arguably makes the primary care environment seem significantly more suitable than secondary care at the time of an acute admission. Indeed some commentators have pointed to primary care as being the ideal environment for ACP,(85) noting its ability to provide many of the conditions identified by research with patients as key to successful implementation of ACP.

In the UK, the fact that most patients still have a single General Practitioner who oversees their care over a long period of time provides an essential element of continuity lacking in any other setting;(86) this is particularly important given the desire of patients to discuss ACP with a professional that is known to them.(41) In addition, GPs and other primary care professionals are likely to know their patients, arguably placing them in an ideal position to facilitate ACP,(38) and tend to see them regularly,(87) giving both frequent opportunity to approach the subject of ACP and chance to address it over time, as a process rather than on a single occasion. Indeed, researchers in one study(38) argued that primary care professionals should take

advantage of their ability to offer continuity of care, focusing more on interpersonal relationships, enabling discussions to develop mutual understanding of patients' wishes for the future.

Despite this apparent suitability of primary care for ACP, research based in this environment seems relatively lacking, particularly in the UK. One review exists, focusing on completion of documented ACP.(88) This suggested that successful ACP was possible in primary care, although it pointed out that significant barriers do exist to this process. A recent empirical study has also been carried out in primary care in the UK, highlighting concerns amongst professionals about policy driven 'tick box' approaches to ACP and suggesting a particular need for further research into identification of patients who would benefit from ACP in this setting.(89)

3.6 Barriers to use of ACP

Following what was seen as limited success in some areas in terms of completion and use of ACP, a number of studies designed to increase ACP use either commented on potential barriers to the implementation and uptake of ACP or investigated them specifically. While the lack of public and professional knowledge and experience of ACP already described would certainly present a significant barrier to its use,(40) a variety of other factors also seem to play an important role.(90)

One group of researchers carried out a systematic review of such studies, looking at advance directive completion in primary care, and identified a number of common themes in terms of barriers.(88) Examining six studies which asked participants about obstacles to completing advance directives, it was suggested that physicians tended to blame 'lack of time', 'low health literacy of patients', 'lack of necessary skills', 'lack of privacy for discussion' and 'patients not sick enough' for their lack of success in offering ACP to patients or putting it into practice. Patients on the other hand referred to 'deferring decisions to physicians or family', 'inconsistency with religious beliefs', 'too distressing to discuss', 'documents too complicated' and 'plan to do it later'.

A number of these 'themes' are supported in other studies. Although many patients find great comfort in discussing ACP,(41) some may of course not find this easy; it is possible that patients are sometimes reluctant to discuss ACP, perhaps due to a fear of death or lack of comfort with talking about such matters with some healthcare staff,(29) and there is evidence that some patients' fears about death inhibit their ability to discuss end of life issues.(90,91) However, with an apparent reluctance on the part of some

healthcare professionals to discuss ACP,(29,33,92) it seems likely that a combination of factors relating to communication between healthcare professionals, patients and family members are involved which can be seen to present barriers to ACP.

Patients have endorsed a view that professionals might be too busy,(36) or lack the time to discuss ACP(93) with significant time constraints in healthcare encounters, and evidence would seem to suggest that this is justified. Observing fifty six discussions about ACP between experienced physicians and their patients, researchers established that discussions tended to be short, with a median duration of 5.6 minutes, and one sided, with physicians speaking for a median of 3.9 minutes.(94) Discussions often failed to explore patients' values in detail, and ended without a specific follow up plan; it was concluded that these consultations may not have addressed ACP in a way that would be of substantial use in future decision making. However, patients themselves may also feel they lack time for ACP, with 40% (n=59) stating that they were too busy with work and family in one study.(93)

The desire of patients to discuss ACP with their families may be strong, with healthcare providers playing a less prominent role(36) where some patients feel that ACP discussions are personal, deserving of discussion with loved ones rather than outsiders such as healthcare professionals, who might change too often for them to be able to establish a relationship conducive to discussion of ACP; such discussions, while valuable, may well not result in usable documented decisions.

Furthermore, while they may want to discuss their wishes with family, some patients find their ability to do this limited by the reaction of those individuals, with many finding that lack of comfort of loved ones in discussing ACP resulted in avoidance and missed opportunities for ACP.(36,41) Acknowledging the discomfort of their relatives in considering these issues, patients in one study tended not to choose those closest to them as proxy decision makers, considering it unfair on them, or believing that they would be too emotional to be rational.(28)

Cultural differences may also have a significant impact,ⁱⁱⁱ with some cultures having very different views of personal autonomy, with greater emphasis on the family or community as the focus of decision making rather than making choices as individuals;(95) furthermore it is possible that even basic assumptions about disease cause and effect may not translate across cultural groups.

ⁱⁱⁱ These issues are discussed further in Chapter 4, (see section 4.5).

Another significant issue may be patients' perception of ACPs relevance to them, with 84% (n=149) in one study believing that ACP was irrelevant,(93) often because they felt themselves to be too healthy (41%, n=59) or because of religious beliefs, with a preference to leave their health in God's hands (43%, n=59). Discussion of issues that patients do not wish or need to focus on may contribute to this feeling that ACP lacks relevance, with one study highlighting inappropriate focus on decisions about cardiopulmonary resuscitation, particularly on admission to hospital, in the absence of broader discussion about care.(33)

Evidence also suggests that focusing on documentation of ACP may fail to capture the full picture of this process: a number of participants in one study felt that completion of documents in the form of an advance directive was unnecessary in achievement of their goals for ACP, with a belief that they had 'completed' ACP in a process of discussion with relatives, and that documentation and formalisation of this process was not needed because their loved ones were now prepared.(36) With many of the goals of patients in ACP being psychosocial,(32) such discussion processes will of course be extremely valuable, and some professionals have been found to subscribe to a view that documentation of ACP is less useful where there exist close and trusting family relationships.(38)

However in failing to establish documented wishes, this kind of process may be seen as an obstacle to ACP in terms of providing assistance to decision making in the future, particularly with regard to communication between professionals. Furthermore, some studies have suggested that patients' own assumptions regarding knowledge of their healthcare preferences present a barrier to ACP, with a belief prevalent amongst elderly patients that their preferences are already known to their trusted friends, family and healthcare providers, even when they have not actually discussed these with them or documented them in any way.(41,93)

Difficulties relating to assessment of patients' capacity to participate in ACP may also form a substantial barrier; in a small UK survey,(46) there was evidence that some of those who felt themselves able to discuss ACP with patients did not in fact believe they had the ability to assess someone's capacity to make one. Other studies have suggested that methodological and procedural difficulties exist in determining individuals' capacity to participate in ACP,(92) leading some professionals to feel safer discussing care planning with family members than with patients themselves.(96) Inaccurate assumptions may also be made by professionals regarding patients' capacity,

particularly in dementia with an erroneous belief sometimes existing that diagnosis of this condition equates with lack of capacity,(74,79) leading to large numbers of patients being unfairly excluded from the process. Furthermore, documentation of ACP and printed information on the subject may not always be pitched at an appropriate level for most patients to understand,(93,97) again resulting in them being unable to participate.

3.7 Facilitators of ACP

Work on improving end of life care has emphasised the need to identify and focus on realistic and achievable goals of care,(98) such as pain and symptom management, avoiding prolongation of dying, achieving a sense of control, relieving burden on loved ones and strengthening relationships; application of these kinds of principles to ACP in a more patient centred form of ACP is argued to be more likely to result in success than concentrating on particular treatments and specific circumstances.(99)

Considering the barriers identified from the perspective of both patients and healthcare professionals, several studies have proposed ways in which these might be overcome. Studies demonstrating the variability of patients' readiness for ACP, as well as their perception of benefits and barriers to the process suggest a need for a customised approach based on individual patient assessment.(90) Consequently researchers have advocated taking into account work and life stresses as well as fears or concerns about ACP, and acknowledging and exploring patients' religious beliefs, including consideration of their faith in ACP discussions;(93,100) professionals should generally aim to learn more about patients' lives and values rather than engaging only in hypothetical discussion of future events.(94)

While time pressures in healthcare encounters mean that long discussions with professionals may often be unrealistic,(94) multiple, brief discussions of ACP could be helpful, carried out in gradual stages in routine outpatient care, with literacy and language appropriate documentation available.(29,93)

In addition several studies identified specific factors which might facilitate successful ACP. Patients in one study believed that healthcare providers were an appropriate group of people to initiate ACP, and that they should reach out and offer ACP to patients.(41) It was felt that ACP was best offered to patients earlier rather than later, and when they were feeling relatively well,(29,41) and that ACP should be established as a routine part of care, perhaps even addressed at a particular age threshold,(41) although hospital policies making ACP routine were not a popular proposal amongst health professionals

in one study.(23) Being known to such healthcare providers was also evidently important, being seen as crucial to some in terms of their belief that their ACP would be respected, so ensuring that ACP is approached by someone familiar to the patient may be of help.(29) Some professionals hold similar views, with one study revealing a belief amongst General Practitioners that 'knowing' relationships, where the patient and doctor know each other, were key to successful ACP.(38)

Involving family and carers more in discussions where possible would also be likely to be beneficial, with patients and professionals seeing this as likely to facilitate ACP,(29) and evidence suggesting that engagement of loved ones, and in particular surrogate decision makers, in the process of ACP can help clarify and document ACP,(101) as well as result in more successful ACP in terms of increasing the likelihood that patients receive care that is consistent with their wishes.(99)

Many studies have focused on improving levels of documentation of ACP,(88) and undoubtedly clear documentation of patients' wishes that is available at the time when decisions need to be made will often be key to ensuring that those wishes are respected.(55) Although it has been suggested that ACP should focus more on interpersonal relationships,(38) it is acknowledged that documentation is still important and likely to be particularly crucial where patients lack close family relationships or see healthcare professionals who are not well known to them. At the present time, such documentation is likely to be in printed or written form; it has been suggested however(102) that as the medical profession gains familiarity with Internet based technology, including social media, integration of these tools into clinical practice may result in significant new opportunity for making, recording and sharing ACPs.

Education will be essential in ensuring successful ACP, both from the point of view of patients and professionals;(95) several studies have proposed public and professional education programmes,(23) with professional training particularly focusing on communication skills,(103,104) including individualised skill sets for specific conditions such as dementia.(74) Education of patients will include helping them to develop understanding of relevant medical conditions, treatments and prognoses in order to establish informed decisions for future care; some researchers are consequently working on interventions to facilitate communication of complex ideas about medical conditions, using for example video decision support tools to enhance informed and consistent decision making in ACP.(105)

CHAPTER 4

Ethical debate and advance care planning

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4.1 Central issues: ethical debate and ACP

- Commentators have criticized the assumption that healthy individuals are able to predict their wishes for future healthcare in order to make decisions for ACP, with various studies providing evidence of instability of individuals' healthcare choices over time. Some also raise doubts about use of ACP from the perspective of 'personhood', questioning the assumption that every individual has a durable identity.
- Criticism exists for the focus of ACP on the principle of autonomy, which may fail to allow proper understanding of the experience of incapacitated patients, and result in poorer communication. Some also argue that the autonomy promised by ACP is illusory: financial constraints mean that choice may not be available in reality, and ACP decisions may be too difficult for many patients to make with true understanding.
- Studies demonstrate a variety of culturally specific beliefs about ACP; some cultures may support fundamentally different views on decision making. Concerns also exist regarding inequalities in provision of ACP, with socioeconomic status likely to have a significant impact on both views and acceptance of ACP and its availability.
- Some fear the potential for coercion in the use of ACP, particularly where complex family dynamics and financial issues are involved; suggestion that ACP has the ability to save healthcare costs may raise further concerns about this possibility.
- Religion is likely to have a significant impact on people's use of ACP, defining their views on decision making and the end of life. The principle of sanctity of life can be seen as allowing and supporting the use of ACP to refuse burdensome and unnecessary treatments.
- While the legal system in England and Wales makes it very clear that deliberate steps to terminate life may not be taken, some have concerns that ACP may be used to obtain euthanasia or assisted suicide, with ACPs to request euthanasia sanctioned in some other countries.

4.2 Introduction

While ACP would seem ethically desirable from the point of view of offering individuals the chance to give expression to their autonomy in such a way that it will continue to have effect should they lose capacity in the future, it has been subject to criticism on a number of issues including the difficulty of predicting future wishes, questions as to whether it effectively supports autonomy and whether this is in fact desirable, concern that it fails to take into account differences in cultural values, and fears that it might conflict with religious beliefs or be seen to be associated with euthanasia or assisted suicide.

This chapter details the basis of these ethical concerns, highlighting some of the important arguments identified in the literature and the evidence brought forward to support them.

4.3 Prediction of future wishes

Despite the attraction for many of providing a means for people to express their wishes for future healthcare in advance of future incapacity, a number of commentators have strongly criticized the concept of ACP, arguing that it is based on a fundamental assumption which they consider to be demonstrably false:(106-108) that healthy individuals have the ability to anticipate and predict accurately their reaction to future situations and disease states, including when death may be imminent, in order to make choices about future treatments.

Such critics refer to a number of studies investigating the stability of patients' choices about future treatment over time. One study,(109) examined the preferences over time of eighteen pregnant women regarding their wishes for analgesia during labour, suggesting that patients' values change over time, and that at certain times expressed values may not be representative of longer held values. Women's preferences were found to shift several times depending on the situation, with strong refusal of analgesia expressed before labour shifting to a clear desire for analgesia during established labour as pain levels increased, but with women returning to their pre-labour preference to avoid analgesia when questioned one month after delivery.

Clearly if a similar changeability in preferences exists with regard to other treatments including end of life care, the concept of ACP is open to criticism. Applying the findings of this study to ACP, researchers looked at the preferences of a group of eighty eight elderly adults for life sustaining medical treatment before, soon after and several

months after hospitalisation for a non life threatening illness.(110) Participants showed less desire for life sustaining treatments during their recovery period than prior to admission, but this was temporary, with their preferences returning to near pre-hospitalisation levels three months later. Furthermore, the most invasive treatments asked about (cardiopulmonary resuscitation and artificial nutrition and hydration) showed the most pronounced changes in judgments: life sustaining treatments seemed particularly context dependent.

The authors of this study concluded that with a fifty-fifty chance that decisions expressed at any given time would change with changes in the individual's health condition it was very difficult to elicit patients' 'true' wishes and that the value of documenting life sustaining preferences in the light of such pronounced contextual changeability was 'suspect'. However they also observed that concluding from this that choices made by patients while experiencing illness or health crisis are somehow more correct would also be challengeable; in most decision making situations one would intuitively assume the opposite, that decisions made dispassionately or with emotional detachment would be preferable to those made with significant emotional involvement.

The findings of this study were reinforced by those of another investigation into changes in patients' preferences for treatment over time, which looked at the effect of changing health states.(111) Here it was found that for some older seriously ill patients, changes in health state were associated with changes in the value they applied to specific outcomes of treatment, with for example those experiencing significant decline in their ability to perform activities of daily living more likely to rate severe functional disability as an acceptable outcome of treatment.

Investigating patients' choices for future healthcare over time without considering the additional complication of hospital admission or other real health events, several earlier studies(112-114) reported moderately stable preferences of individuals for life sustaining treatment over time, with stability of choices improved by review of decisions, and decisions regarding life sustaining treatment more stable for refusal than preference for treatment. However where individuals changed their preference, they were often unaware of this, raising the question of how considered such decisions tend to be,(113) but also leading to concerns about previously documented wishes;(107) if patients do not recognize that they have changed their views, they are unlikely to alter existing documented wishes, which will therefore continue to misrepresent their views and may result in treatment that is no longer in accordance with their wishes.

These findings were consistent with a body of psychological research on ‘affective forecasting’,(115) which demonstrates that people are generally relatively poor at judging their future emotional states, making systematic errors in predicting their reactions and choices in future situations. Furthermore, such research suggests that preferences tend to be formed spontaneously when they are expressed rather than being accessed from a consistent and stable set of values, and therefore highly context driven. This would arguably be even more likely to be the case when considering issues such as end of life where individuals have little direct personal experience.(107,113)

For some,(107,116) these issues provide a strong argument against the use of ACP in the form of advance decisions to refuse treatment and an argument for powers of attorney as a better and more reliable option: the appointment of someone to act as an attorney involves a much simpler, more manageable choice than making decisions about specific treatments, and may require little change from current practice where families often act informally for patients. Use of powers of attorney might also improve decisions, since the attorney will know a great deal more at the time of making a decision than the individual would have done when making a decision in advance.

However, there may be evidence against this view: in a systematic review of sixteen studies involving accuracy of surrogate decision makers’ prediction of patients’ treatment preferences, it was found that overall patient chosen and next of kin surrogates failed to predict patients’ actual end of life treatment preferences in a third of cases.(117) In addition, this review demonstrated that neither choosing of the surrogate by the patient nor prior discussion about views on end of life issues improved surrogates’ accuracy. Based on hypothetical scenarios, these findings may not necessarily correlate with the accuracy of surrogates’ decisions in real life scenarios, but still raise questions about their use. Furthermore, other studies have demonstrated that surrogates’ decisions are often strongly associated with their own treatment preferences about the use of life sustaining treatments rather than those of the patient.(118)

Addressing general concerns about the difficulties in prediction of future wishes more philosophically, some have considered an underlying question about ‘personhood’ to have potentially important implications for ACP.(119) Questioning the ‘self paternalistic’ assumption that every individual has one ‘true’ identity, best able to make long term decisions on the individual’s behalf,(2) some argue that our current and past or future ‘selves’ are not in fact the same ‘person’, or may at least be substantially changed. This debate leads to inquiry as to what extent ‘personhood’ equates with

‘capacity’, and whether the incapacitated person envisaged when making an ACP is the same ‘person’ as that making the decision. Pointing out that the theory of personhood underlying ACP requires that previous wishes, necessarily based on previous interests and values, bind the future person despite potentially significant changes in values and interests, some have argued that perhaps we should not be able to bind our future selves with decisions made in advance.(2,120) Citing the example of the ‘pleasantly demented patient’, who despite documented wishes to the contrary, seems content, even happy, with life, some suggest that perhaps the currently apparent wishes and interests of patients, regardless of their capacity, might appropriately take precedence over previously expressed competent wishes.(108) Whatever the level of consideration given to the views of such patients, the existence of incompetent but potentially alert patients who continue to have subjective experiences, such as those suffering from dementia, is a significant complicating factor in the use of ACP,(121) where difficult balances may need to be struck between previous and current interests of patients.(122)

4.4 Problems with autonomy

Over the course of the latter part of the twentieth century, the system of ‘principlism’ has evolved to be the presiding theory of medical ethics. First proposed in the 1980s by two American Philosophers, Tom Beauchamp and James Childress, this approach provides four principles, ‘autonomy’, ‘beneficence’, ‘non-maleficence’ and ‘justice’, as a framework by which bioethical problems or dilemmas can be analysed and solved.(123) Developed at a time of considerable social change with focus on human rights, particularly within the field of medicine, autonomy has emerged as the most powerful of these principles, at the heart of Western medicine’s current commitment to individual choice and patient empowerment.

With a general interpretation of respect for autonomy including the protection of patients’ ability to make decisions, ACP has seemed to provide an ideal tool to support the autonomy of patients who have lost capacity to make decisions for themselves;(124) belief in the principle of autonomy has thus arguably contributed to the existence of support for ACP sufficient to result in legislation in many countries.

However, despite the apparent pre-eminence of the theory, principlism has not been without criticism, with concerns about the basis for selecting the four principles, the lack of a set of rules with which to order them, and consideration of social context.(119)

Some commentators have strongly criticized the power afforded specifically to the principle of autonomy, arguing that in Western society a point has been reached where autonomy is valued too highly and that too great a focus on autonomy could be damaging to societies which should in fact perhaps place greater emphasis on consideration of others within the community, or communitarianism.(119,125) Others criticize its pre-eminence in the area of end of life care, suggesting that it fails to guide respect for individuals effectively, and that end of life care would be better served by promotion of community values or systems and pathways of care.(126,127) It has also been argued that focus on the autonomy principle results in failure to develop a proper understanding of the situation of patients who lack capacity, by blurring the crucial distinctions between individuals with and without capacity, meaning that important elements of such patients' experiences are ignored.(120)

Furthermore, the dominance of autonomy as a bioethical value in Western societies is not necessarily matched in all other cultures, perhaps particularly those where there is a somewhat more communitarian way of thinking less centred on the individual.(125) Without awareness of and sensitivity to such differences, the principle of autonomy, and arguably concepts relying heavily on this principle, such as ACP, might greatly complicate cross-cultural communication within healthcare.

Some have raised fears that such is the focus on autonomy within the field of healthcare that normal communication between doctors and patients could be damaged, with patients 'abandoned to their own autonomy',(119) by 'inverse paternalism'.(128) Here, it is argued, an imbalance could occur between patients holding traditional views about 'doctor knows best' and doctors with overvalued belief in the patients' sense of autonomy. Rather than the 'patient centred' consultation aspired to, where decisions are made in partnership, patients could be left to fend for themselves with doctors expecting them to make their own 'autonomous' decisions. Some see ACP as problematic in this way, with the temptation sometimes to transfer responsibility of complex and difficult treatment decisions to the patient.(25)

While autonomy may be held to be the key value guiding medical decision making, including anticipatory decision making, there also exists a question as to whether there is in fact opportunity for patients to exercise true autonomy within current healthcare environments. It is well known that financial pressures significantly compromise the choices available to patients, with commentators highlighting the fact that the necessity to make decisions about allocation of scarce resources will often make it impossible to

respect patients' autonomous choices: distributive justice instead requires decisions to be made 'between autonomous choosers'.(129) This is likely to be true in the area of end of life care as in any other field, with cost and supply frequently a key determinant of place of death rather than choice.(106)

Evidence of a predominance of physicians' values in some decision making, especially regarding life sustaining treatment,(59) might suggest a further illusory aspect to autonomy in ACP, with some commentators arguing that much of what is understood to be 'successful ACP' with patients' previously expressed autonomous wishes duly followed at the end of life, simply occurs because their physicians agree with their decision; where healthcare professionals disagree with patients wishes, they may be much less likely to be followed.(130)

It has also been suggestedⁱ that some decisions, particularly in ACP which may involve multiple different decisions all of a potentially momentous nature and involving complex balancing of benefits and risks, are simply too open ended and nebulous for patients to grasp either emotionally or cognitively, especially when ill, or for their doctors to explain effectively to them.(106,107) Such situations, where it may be impossible realistically to obtain informed consent, would clearly fail to offer patients a truly autonomous experience in decision making.

Finally, evidence from some studies on ACP might be taken to raise questions as to whether patients actually always want to exercise autonomy in this area, at least as understood by the ability to make decisions for themselves. One study found that very few individuals wanted an ACP that required them to state precise directions about medical care;(131) they did not wish to 'micromanage' their future care, but rather were in favour of opportunity to make personal statements about their values and goals for care. In addition, the vast majority (91%) wanted surrogate decision makers to have at least some leeway to override their written wishes if this seemed in their best interests.

Another study of patients on dialysis sought their views as to whether they would want dialysis continued or stopped should they develop advanced Alzheimer's disease.(132) When subsequently questioned about how strictly they wished their decision to be followed, while some wished this to be followed exactly, 61% were happy to allow surrogate decision makers to override their decision if it were in their best interests.

ⁱ The concerns of healthcare professionals about 'informedness' of patients in ACP are discussed further in Chapter 3 (see section 3.3.4).

In a study analysing data from two large investigations of end of life and elderly care in US hospitals, more than two thirds of elderly patients preferred resuscitation decisions to be left to their families and their doctors rather than have their own stated preferences followed if they were to lose the capacity to make decisions.(133) A more recent study looking at some of the same data similarly concluded that the majority of sick elderly patients preferred to rely on their family or physician to make resuscitation decisions rather than follow their previously expressed wishes.(134) However this also demonstrated a significant association between patients' previous experience of ventilator treatment and preference for autonomous decision making, with a desire for their wishes about resuscitation to be followed.

This work perhaps suggests that where patients lacked confidence in the accuracy of their prediction of their wishes, due to lack of understanding or experience in the treatment in question, they preferred to leave such important decisions to others whom they trusted, but it can also be reasonably understood as strongly challenging the view that all patients want unlimited autonomy in decision making.

Several commentators have attempted to provide answers to the various problems raised by the principle of autonomy with regard to ACP. 'Respect for persons' has been proposed as 'an ethical principle broader than autonomy', to include concepts such as dignity and individuality, involving a duty to protect patients who are unable to make decisions for themselves.(135) Using this principle, it is argued, professionals and surrogate decision makers should consider the life story of a person and make decisions consistent in the light of the person's previous choices, with the person's known interests and values placed in the context of their current situation. Suggested as an alternative to the US concept of 'substituted judgment', where surrogate decision makers attempt to respect individuals' autonomy by making the decision it is thought they would have made had they retained capacity, this description in fact lies very close to the UK statutory definition of 'best interests' on which holders of LPAs are required to base their decisions.

It has also been suggested that more flexibility should be afforded to patients in expressing their preferences about future care,(116,131) with ACP being used to document information about patients' views about treatments and goals for care as well as the extent to which they wish future decision makers to be able to override these views. Furthermore, helping patients to focus on realistic goals for care may more

effectively meet the needs of patients making difficult decisions, offering them greater choice while allowing them to maintain their autonomy.(103)

Others however feel that a more straightforward answer altogether is called for. Perhaps with better communication between doctors and patients, leading to a reduction in patients' fears about the future, ACP may in many cases become 'redundant'.(119) Alternatively it has been argued that application of principles of palliative care, the advocacy of home care and hospice services, and provision of practical and emotional support to patients who have lost capacity, while ensuring that resources are maximised to enable choices to be respected, are expressions of true understanding and respect for patients' autonomy, rather than placing on them the additional burden of unmakeable decisions which it may then be impossible to follow.(106)

4.5 Cultural differences in ethical values

A number of researchers have looked at the effect of ethnicity and culture on ACP, with evidence that these are important though highly complex factors in patients' decision as to whether to participate in ACP. One qualitative cross-cultural study(136) revealed shared beliefs that dying patients deserved a say in end of life treatment and that ACP might help guide that treatment, but at the same time showed that European, African, Mexican and Hispanic Americans held a variety of ethnic-specific beliefs regarding end of life care, ACP, and healthcare in general. Another study which found ethnic differences in the use of ACP by patients with cancer,(137) although identifying a variety of seemingly relevant factors which also varied by ethnicity, was unable to identify any which accounted for difference in ACP use.

Many of the ethnic differences observed in attitudes to ACP may be explained by significant variation in cultural ethical frameworks, with a number of studies illustrating the point that Western bioethical principles may not always be culturally familiar or appropriate. In a qualitative study of elderly African Americans,(138) for example, participants failed to endorse the principle of autonomy in ACP, tending to defer or deflect decisions about future treatments to other family members.

Other ethnic groups have been shown to have ethical views even further removed from those perhaps anticipated when proposing ACP, with autonomy being perceived as an isolating rather than empowering concept in some cultures which value a more family centred decision making style.(139) In Japan, a questionnaire survey(140) found that most participants were happy to consider expressing their views to family and physician

orally, but not as a written document, and that they felt that it was permissible for family and physician to interpret their expressed wishes loosely. Researchers in this study commented on a significantly different cultural background in Japan, with a historical lack of assertion of rights and a cultural belief that talk of rights of individuals suggested conflict, with those asserting rights considered selfish and conceited. Similar findings were evident in another survey where Korean American elderly patients did not believe that their opinions and personal desires about treatment were relevant in treatment decisions.⁽¹⁴¹⁾ Here, decisions were considered the responsibility of the family, who had a strong sense of duty through filial piety to prolong the life of their relative for as long as possible.

Similar preference for family centred decision making may also exist in other groups, with a study of elderly patients in the US suggesting that Mexican Americans and Caribbean Hispanic people prefer family centred and collective decision making to individual or autonomous decision making.⁽⁵⁷⁾

Significant cultural differences in understanding of ethical obligations in relation to truth telling within healthcare⁽¹⁴²⁾ are also likely to have a significant impact on ACP, with for example Korean American and Mexican American patients less likely to believe that the truth should be told about diagnoses and less likely to believe that patients should make decisions about the use of life support.⁽¹⁴³⁾ Even some European cultures may, in the relatively recent past at least, have significantly different ethical values relevant to ACP, with most patients surveyed in a Greek study said to be unaware of their rights with regard to truth telling in medical practice, and autonomy felt to be a vague and poorly understood concept;⁽¹⁴⁴⁾ only a third felt sure that a person should be told about a terminal illness and even those who supported truth telling tended not to base it on consideration of autonomy.

4.6 Inequalities, incentives and coercion

If ACP remains an ethically desirable concept, offering patients the ability to retain control over their future care, an important concern will be trying to ensure that it is equally available to all patients, with effort made to address factors which appear to affect this. However, as in many areas of healthcare, the question of health inequalities in relation to ACP is a complex one, with one large study based on analysis of data from a large national survey of sixteen thousand deaths,⁽¹⁴⁵⁾ showing rates of use of ACP

significantly higher in patients who were white, female, had private medical insurance, higher incomes, and college educations.

While cultural differences in ethical values may result in significant variation in the acceptance and use of ACP, factors relating to socioeconomic status have been shown to result in variations in ethical viewpoints within ethnic groups, with wealthier, more educated individuals perhaps more likely to hold views closer to a 'Western' ethical framework. Furthermore, many other factors are likely also to have an impact both within specific ethnic groups and across wider populations. Lower rates of ACP in African Americans, for example, have sometimes been explained by unwillingness of this group of patients to share views and feelings with their physicians,(136) related to a long history of distrust of a white dominated healthcare system.(139) In terms of population wide factors, further work on education has highlighted the fact that most forms for informing patients about ACP and documenting wishes in the US required a literacy level for use considerably higher than the national average in America,(97) meaning that use of ACP may effectively be impossible for a large proportion of the population; when researchers devised a redesigned ACP document to meet the literacy needs of most American adults, this was preferred by most patients and resulted in higher six month completion rates than a standard form.

Cost of ACP for patients will also be a significant concern in terms of its availability to all members of a population. Although professional guidance suggests that ACP should be viewed by healthcare professionals as a part of normal good practice, and patients should not therefore be charged for advice when carrying out ACP,(19,21) if individuals wish to seek legal advice it is very likely that this will incur a fee. With registration of a LPA in the UK, for example, currently £130 on top of any solicitor's fees, although legal aid may be available for some,ⁱⁱ some elements of ACP might reasonably be considered to be well beyond the financial reach of a large proportion of the population. However there are other important financial implications to consider with regard to ACP. As well as supporting individuals' autonomy, ACP's ethical value as a way of avoiding burdensome, futile and unwelcome interventions, can be viewed from the

ⁱⁱ Patients are advised on the NHS Choices website to contact the Law Society for further information on means tested assistance with legal advice, which may be available for health and welfare LPAs, though not for property and affairs. Available from: <http://www.nhs.uk/CarersDirect/moneyandlegal/legal/Pages/applying-for-power-of-attorney.aspx>

perspective of healthcare systems as well as patients. While modern medicine increasingly offers interventions which have the ability to prolong life, these, in common with many new technological developments, are often associated with significant cost. Unwanted hospital admissions and inappropriate interventions may be of importance from the point of view of patients' autonomy, but in healthcare systems where resources are limited, substantial expenditure towards the end of life⁽⁶³⁾ on patients whose benefit from this spending may be minimal could also be of ethical concern. With evidence suggesting that ACP has the potential to reduce the expenditure of healthcare resources, particularly in terms of hospital admissions,^(54,64) it is arguable that ACP might fulfil an important role in terms of the ethical principle of justice in helping to control inappropriate spending on unwanted and inappropriate care. However, for some,⁽¹⁰⁶⁾ the very possibility that ACP may save health services money raises grave concerns that economic drivers might exist in relation to ACP; on a background of the expense of life sustaining treatments, moves towards reduced intervention in end of life care could play a role in promotion and support of ACP by healthcare services. One commentator⁽¹⁴⁶⁾ has suggested that marketplace forces and rationing in the healthcare environment are likely to have confused patients about healthcare services' efforts to promote choice and limit the use of aggressive care at the end of life, with public fears developing that ACP may lead to the withholding of desired care, and those patients still interested in ACP more likely to see it as a means of ensuring that they obtain care than of refusing unwanted care.

The relevance of these concerns is highlighted by the recent and ongoing US controversy regarding 'death panels',ⁱⁱⁱ where proposals for cost cutting advisory boards in an attempt to stem the rapidly rising costs of healthcare were dramatically linked to further proposals supporting reimbursement of healthcare professionals for the promotion of end of life care planning. Similar public and media outcry arose when it emerged that the UK Department of Health, in the form of a number of local commissioning bodies, had offered financial incentives to NHS hospital Trusts for

ⁱⁱⁱ Pikert K. The healthcare proposal that spawned the death panels lie is back. Time Magazine 25 July 2013. Available from: <http://nation.time.com/2013/07/25/the-health-care-proposal-that-spawned-the-death-panels-lie-is-back/>

implementation of the Liverpool Care Pathway,^{iv} a system originally devised to support the provision of effective and appropriate palliative care to patients at the end of life but later mired in controversy amid accusations that it was used without patients' consent and treatments withdrawn resulting in hastening of death.

When considering financial issues influencing ACP use, the question of coercion is clearly of great importance. Healthcare professionals anxious to meet targets or reduce healthcare expenditure, as well as relatives, carers or friends interested in potential inheritance or simply exhausted with provision of care and support might all potentially have ulterior motives in carrying out ACP with patients. In order to be valid, ACPs should of course show no evidence of coercion, with consent to make an ACP being voluntary in the same way as in all treatment decisions. However, when setting up powers of attorney for property and financial affairs there will be very obvious concerns about ensuring that an individual's decision to hand over control of his finances to another is free from coercion, and other forms of ACP might very well also be susceptible to this problem,(34) particularly perhaps where there is significant responsibility, including financial burden, on families in taking care of an elderly or seriously ill relative. Some have suggested(119) that a degree of 'influence' might be necessary and acceptable in order to support a patient's autonomy; however, the point at which an acceptable degree of influence or persuasion to support an elderly person's autonomy becomes unacceptable coercion is likely to be very difficult to judge.

4.7 Religion, euthanasia and assisted suicide

It is known that many individuals have spiritual or religious beliefs that they believe would influence their decision making in serious illness,(147) and there is evidence that people also make use of religion in coping with such illness.(100,148) Religious beliefs reduce patients' sense of loss of control and helplessness and provide a cognitive framework that can reduce suffering and increase purpose and meaning.(148) In addition, prayer may reduce the sense of isolation and loneliness, and make patients feel they can have some influence over their condition, perhaps by asking God to act on their behalf.

^{iv} Bingham J. NHS millions for controversial care pathway. The Telegraph 31 Oct 2012. Available from: <http://www.telegraph.co.uk/health/healthnews/9644287/NHS-millions-for-controversial-care-pathway.html>

It is therefore unsurprising that religious views may have a significant effect on people's use of ACP. In a review exploring the spiritual beliefs that may influence treatment preferences for African Americans,(149) it was suggested that such beliefs strongly guide many of these patients as they cope with illness at the end of life. With a common theme of 'God (not healthcare providers) has the last word', this study identified a variety of sometimes inconsistent beliefs. It was felt that belief in sanctity of life and that life and death are in the hands of a higher power, might lead to refusal of life sustaining treatments being seen as a form of assisted suicide or euthanasia. However in contrast, for some the belief in divine power and intervention seemed to result in a conviction that there was no need for aggressive treatments because God could take care of things. A similar paradox has been commented on elsewhere, with a review of advance directives in Spain(150) noting a contrast between the influence of traditional Catholic morality with the notion that life belongs to God and should not therefore be limited in any way, and the fact that the official doctrine of the Church is against futile life support and the Catholic Church was the first institution in Spain to distribute living wills.

In fact, religious beliefs, and in particular Western Judeo-Christian theology, have arguably been a key component of ACP from the very start of its development. In the American case of *In Re Quinlan*,^v which established a right to refuse life sustaining treatment, considerable comment was made on the Roman Catholic beliefs of the father and guardian of the patient. The court remarked on the fact that he had discussed his decision with his priest to confirm its 'moral rightness', and allowed the evidence of a Catholic bishop as *amicus curiae* to explain the position of the Church on various matters relating to the case.

In this context, reference was made in the Quinlan case to the 'sacredness of life'. The doctrine of 'sanctity of life' holds that all life, even at a terminal stage, is a gift from God and has an inherent and infinite value entitling it to protection from unjust attack,(151) and is predominant in many religions, including the Judeo-Christian tradition.(152-155) Superseding judgments of 'quality of life', the sanctity of life is not however normally considered to be absolute in the sense that it must be preserved at all costs. Consequently, treatments that are unduly burdensome or likely to prolong suffering for example are not a moral imperative and may be legitimately refused,

^v 70 N.J. 10, 355 A.2d 647 (1976)

withheld or withdrawn; such treatments are often referred to as ‘extraordinary means’ in Western Christian theology, being ‘extraordinary’ in the moral sense of not being obligatory despite the fact that they may be sometimes be considered medically quite ‘ordinary’.(156)

While termination of a procedure considered to constitute extraordinary means would not therefore usually be considered to amount to euthanasia, and refusal of such treatment would equally not be considered suicidal, any action that wilfully facilitates death would be antithetical to most God centred moral frameworks; consequently ACP could not be used as an instrument of euthanasia to specify or require any action that would intentionally result in premature or contrived death.(155)

From a legal point of view, the doctrine of sanctity of life has long been central to common law decisions in England and Wales relating to end of life, generally imposing a strong presumption in favour of preservation of life except in exceptional circumstances (*In Re J*).^{vi} In considering refusals of life sustaining treatment, including refusals made in advance, the courts have however supported a view that this doctrine must sometimes yield to the principle of self determination or personal autonomy. While they have ruled that in the case of such refusals of treatment there should be no question of the patient having committed suicide, and that similarly there is no question of the court sanctioning deliberate steps to terminate life (*Airedale NHS Trust v Bland*),^{vii} some have strongly criticized these decisions, and the professional guidance derived from them,(157) as inconsistent and failing to place sufficient value on the sanctity of life, leaning more towards assessment of ‘quality of life’.(158) Others, however, fear that the courts may sometimes place too great an emphasis on sanctity of life (*W v M and Others*),^{viii} as a result failing to give sufficient recognition to the previously expressed wishes of patients.(159)

This debate notwithstanding, despite some having concerns that ACP might be used as a means to obtain euthanasia or assisted suicide,(155) statutory provisions for ACP in the UK are clear (MCA 2005 s.62), and it seems evident that ACP cannot be used to request euthanasia or assisted suicide in the UK. However, in countries that allow the use of euthanasia, such as the Netherlands, Belgium and Luxembourg, ACP or advance directives for euthanasia (ADEs), may be used to direct physicians to carry out

^{vi} [1991] Fam. 33.

^{vii} [1993] 2 WLR 316.

^{viii} [2011] EWHC 2443 (Fam).

euthanasia in certain circumstances.(160) Nevertheless, even in such jurisdictions, strong criticism exists for the concept of ACPs that request euthanasia, in terms of inconsistency with legal requirements for 'due care' in carrying out euthanasia as well as ethical concerns with ACP more generally such as the problem of accurate prediction of wishes, with some considering these requests simply unfeasible legally, ethically, and practically.(161) A particular concern for some has been the use of ADEs in patients suffering from dementia, who may now seem accepting of a life they formerly rejected.(121) Perhaps as a result, it seems that despite legislation that apparently allows opportunity for ACP requesting euthanasia, this rarely has effect in terms of the intentional killing based on prior wishes of patients who lack capacity:(160) in a survey of 434 elderly care physicians in the Netherlands, although most had experience of treating patients with dementia who had made an ADE, only three had ever intentionally ended such a patient's life, and in each of the five cases involved the patient had been judged to retain full capacity to make the decision at the time the euthanasia was carried out.

Considering the idea of ACP used to express wishes for euthanasia or assisted suicide, some commentators having suggested that the potential for combination of ACP with euthanasia presents particular concerns in compounding existing doubts about both processes, with questions about personhood even leading to the idea that euthanasia might represent a form of homicide in the sense of a directive resulting in killing of a different or at least substantially changed individual.(162)

Debate persists in the UK about euthanasia and assisted suicide, with the medical profession, traditionally opposed to assisted dying, increasingly taking part in this debate: the Royal College of Nursing has adopted a neutral stance on the issue,^{ix} while the Royal College of General Practitioners recently announced a consultation on the matter.^x Cases continue to be brought in the English courts seeking further clarification of the legal position on a number of issues relating to a 'right to die' and assisted

^{ix} RCN. Press release. RCN moves to neutral position on assisted suicide. July 2009. Available from:

http://www.rcn.org.uk/newsevents/news/article/uk/royal_college_of_nursing_moves_to_neutral_position_on_assisted_suicide

^x RCGP. Press release. RCGP launches membership consultation on assisted dying. May 2013. Available from: <http://www.rcgp.org.uk/news/2013/may/rcgp-launches-membership-consultation-on-assisted-dying.aspx>

suicide (*R (Pretty) v Director of Public Prosecutions*,^{xi} *R (Purdy) v Director of Public Prosecutions*,^{xii} *R (Nicklinson) v Ministry of Justice*^{xiii}), though to date the Courts have resisted any suggestion of a change in the law making it clear that this should be a matter for Parliament to decide. In fact this is an area that has been addressed by the Government several times in recent years, with some consideration also given to ACP in relation to these matters.

In 2005 the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill,⁽¹⁶³⁾ although divided on a number of issues,⁽¹⁶⁴⁾ agreed on recommendations for further debate in parliament and within clinical services; it did consider evidence relating to the use of ACP in this area, particularly with respect to the situation in Belgium and The Netherlands, but did not refer to this issue in its final recommendations. Subsequently, in January 2012, the Commission on Assisted Dying, led by Lord Falconer, published its findings.⁽¹⁶⁵⁾ Heavily criticized for its apparent bias^{xiv} with predominant involvement of known supporters of euthanasia and assisted suicide, the Commission did comment in its proposed framework to underpin assisted suicide in the UK on the potential use of ACP in this area. It was suggested that ACP might conceivably be used as a means for individuals to record their wishes about assisted suicide, and that such a record could provide useful evidence of consistency of wishes were someone subsequently to make an active request for assisted suicide. However, as part of the proposed safeguards to this process it was made clear that ACP requesting assisted suicide could never be used to allow this to take place with a person now lacking in capacity.

However, some have argued that,⁽¹⁵⁸⁾ while *actions* to assist suicide are clearly unlawful (*R (Pretty) v Director of Public Prosecutions*), the law as it stands appears to require that patients' refusals of treatments, which would include advance decisions to refuse treatment, be respected even if such refusals are suicidal (*Airedale NHS Trust v Bland*,^{xv} *Secretary of State for the Home Department v Robb*^{xvi}). Should this be the

^{xi} [2002] 1 All ER 1, [2001] UKHL 61.

^{xii} [2009] UKHL 45.

^{xiii} (2013) EWCA Civ 961, (2013) MHLO 65.

^{xiv} Care Not Killing. Press release: Falconer report on euthanasia "biased and flawed" says Care Not Killing. Jan 2012. Available from:

<http://www.carenotkilling.org.uk/press-releases/falconer-report-biased/>

^{xv} [1993] 2 WLR 316.

^{xvi} [1995] 1 All ER 677.

case, it would present significant difficulty in terms of the importance normally afforded to the doctrine of the sanctity of life as well as seeming to contravene the intention of the Suicide Act 1961.

Addressing this issue, one commentator referred to a case where a young woman who took an overdose and later set fire to herself was found while unconscious during treatment to have 'DNR, do not resuscitate' tattooed on her chest.⁽¹⁴²⁾ Discussing the need for proof of a patient's wishes in circumstances where refusal of treatment was likely to result in death, it was suggested that the criminal standard of proof, 'beyond all reasonable doubt', would be closest to that required to establish such a patient's autonomous preferences. Others have contended that this is another example of the principle of autonomy being afforded too great importance,⁽¹⁶⁶⁾ suggesting that an individual's right to autonomy is not unassailable, with public interest in the prevention of suicide being a potentially powerful argument to be weighed against this in making medical decisions.

Clearly these are complex issues, but clarity will be essential regarding any association of ACP with euthanasia, suicide or assisted suicide, at least in the UK. In an independent review of the Liverpool Care Pathway following the public controversy regarding this instrument,⁽¹⁶⁷⁾ the review panel noted that the most damaging of the concerns expressed about the pathway had been the belief that putting someone on it was a way of deliberately hastening their death. While some of the recommendations of the review involved the effective use of end of life care planning, clearly any negative beliefs about ACP with regard to euthanasia or assisted suicide could be similarly damaging.

CHAPTER 5

Healthcare policy and guidance on advance care planning

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5.1 Central issues: healthcare policy and guidance on ACP

- NHS policy favours ACP with a variety of initiatives promoting its use.
- The National Institute for Health and Clinical Excellence has published Quality Standards relevant to use of ACP: ‘end of life care for adults’, ‘dementia’ and ‘supporting people to live well with dementia’.
- The National Gold Standards Framework provides training and accreditation to healthcare professionals, aiming for a basic level of ACP for all patients at the end of life in the form of preferred place of care and resuscitation preferences.
- Royal College of General Practitioners policy and the End of Life Care Patient Charter support and promise the use of ACP with patients at the end of life in primary care.
- Professional guidance has been produced on or relating to ACP by a number of bodies including the British Medical Association, Royal College of Physicians, General Medical Council and National End of Life Care Programme.
- Key recommendations of these guidance documents include:
 - ACP should be offered routinely, in primary care or outpatient departments.
 - ACP should be offered to patients at the end of life, with chronic conditions, and those at risk of loss of capacity.
 - Patients should be supported to participate in ACP as far as possible, but must have capacity in order to participate.
 - ACP should be carried out as a process, and tailored to the individual patient.
 - Decisions made as part of ACP should be documented and shared appropriately.
 - ACP should be subject to regular review.

5.2 National Health Service policy on ACP

Ever increasing focus in UK healthcare policy on patient centred care,(168) shared decision making between patients and professionals,(10,169) and respect for patients' autonomy as essential aspects of good practice,(170) makes ACP, a concept with an apparently high potential for delivering these ideals, appear particularly attractive.

The idea of an intervention that can be seen as empowering patients and enabling them to continue to exercise a degree of autonomy when they have lost capacity, while at the same time both simplifying and enhancing the quality of decision making for patients who have lost capacity, with resulting improvement in experience of care,ⁱ has understandably gained ACP substantial support with policy makers in the UK healthcare field, with evidence in the form of a variety of publications and initiatives that NHS policy is strongly in favour of ACP. It is possible that suggestion(54,64) of potential savings in health service resources through reduction in hospital admissions and use of services has served to further strengthen interest in this area.

In 2008, the Department of Health published the NHS Next Stage Review, a review led by Lord Darzi,(170) which emphasized the importance of giving patients more control, allowing them the opportunity for greater choice in their healthcare and to be partners in decision making about their care. Specifically, the review recommended the use of 'personalized care plans' for all patients with long term conditions.

Over recent years, the National Institute for Health and Clinical Excellence (NICE) has produced a set of 'Quality Standards',ⁱⁱ designed to drive and measure quality improvements in priority areas of care, '*supporting the Government's vision for a health and social care system focused on delivery of the best possible outcomes for people who use services, as detailed in the Health and Social Care Act 2012.*' Several of these support and promote the use of advance care planning with patients.

The quality standard for end of life care for adults (QS13), requires that '*people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences with the opportunity to discuss, develop, and review a personalized care plan for current and future support and treatment.*' This may include the use of advance statements or advance decisions to refuse treatment, as described in National End of Life Care Programme guidance.

ⁱ Evidence for these and other benefits of ACP is discussed in Chapter 4.

ⁱⁱ Further information on these Quality Standards is to be found on the NICE website. Available from: <http://www.nice.org.uk/guidance/qualitystandards/qualitystandards.jsp>

Two standards relating to dementia refer to ACP, and NICE also refers to it in specific guidance on dementia.⁽¹⁷¹⁾ The dementia quality standard (QS1) requires that *‘people with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carers, about the use of: advance statements, advance decisions to refuse treatment, Lasting Powers of Attorney, and preferred place of care’* while the quality standard for supporting people to live well with dementia (QS30), requires that people *‘have choice and control in decisions affecting their care and support.’*

The NHS End of Life Care Programme,ⁱⁱⁱ now part of the new NHS Improving Quality (NHS IQ),^{iv} was established to promote high quality, person centred end of life care for adults, and provided strong support for ACP, giving information and training to professionals as well as patients and lay people, and promoting initiatives for its use.

In addition, the National Gold Standards Framework Centre in End of Life Care (GSF),^v originally an NHS supported programme developed from primary care, aims to improve primary palliative care, provide training and support to healthcare professionals to enable them to provide a gold standard of care to patients at the end of life. Providing accreditation to care homes, GP surgeries, community and acute hospitals, the GSF particularly supports the use of advance statements to define wishes for future care and has produced its own document for recording these. A key focus of the GSF is on establishing with patients thought likely to be in the last year of life, their preferred place of care (PPC), that is, where they would like to be cared for at the end of life, as well as their preferences regarding resuscitation in the event of cardiopulmonary arrest.

Several of the UK medical Royal Colleges, as well as various other professional bodies, have also contributed to policy in together producing specific professional guidance on ACP;⁽¹⁷²⁾ in addition, the Royal College of General Practitioners (RCGP) have issued a policy statement on end of life care,^{vi} which endorses and supports the promotion and use of ACP in primary care, as well as publishing the RCGP End of Life Care Patient

ⁱⁱⁱ Further information on the NHS End of Life Care Programme is available from:
<http://www.endoflifecare.nhs.uk>

^{iv} Further information on NHS Improving Quality is available from:
<http://www.england.nhs.uk/ourwork/qual-clin-lead/nhsiq/>

^v Further information on the National Gold Standards framework Centre is available from: <http://www.goldstandardsframework.org.uk/advance-care-planning>

^{vi} RCGP. End of Life Care Strategy. January 2009. Available from:
<http://www.rcgp.org.uk/policy/rcgp-policy-areas/end-of-life-care-strategy.aspx>

Charter^{vii} and associated guidance,^{viii} which promises patients support in identification and communication of choices and wishes about future care.

5.3 Professional guidance on ACP

Support in policy for the concept of advance care planning and a general belief that promotion leading to increased use of ACP in practice is desirable has led to the development of a variety of professional guidance on the process from a number of organizations. Brief descriptions of these guidelines in the ensuing pages are followed by two tables summarizing the key messages and recommendations of these documents regarding both the use and interpretation of ACPs as well as the process of making them.

5.3.1 *The British Medical Association*

The British Medical Association (BMA) has produced several guidelines that include information relating to ACP. The result of deliberations of the BMA's Medical Ethics Committee, these together provide quite comprehensive information on the legislative framework surrounding use of ACP, with particular reference to the MCA 2005, and are intended to complement existing statutory guidance in the form of the MCA 2005 Code of Practice. In addition, they aim to highlight a variety of ethical issues involved in the use of ACP. However these are not clinical guidelines, and their references are almost exclusively to statute and case law; they do not provide any information on the research evidence regarding use of ACP in practice.

5.3.1.1 Advance decisions and proxy decision making in medical treatment and research

This guidance⁽¹⁷³⁾ focuses on provisions allowing patients with capacity to make advance decisions to refuse treatment and to appoint proxy decision makers under the MCA 2005 in England and Wales, as well as explaining the legal situation in Scotland and Northern Ireland. It also provides details on the definition and assessment of mental capacity under these jurisdictions.

^{vii} RCGP / RCN End of Life Care Patient Charter. 2011. Available from: <http://www.rcgp.org.uk/endoflifecare>

^{viii} RCGP. Matters of Life and Death: helping people to live well until they die. General Practice guidance for implementing the RCGP/RCN End of Life Care Patient Charter. August 2012. Available from: <http://www.rcgp.org.uk/endoflifecare>

The BMA suggests a number of specific situations where ACP may be useful, as well as making recommendations for health professionals regarding assessment of capacity, recording and storing of ACPs and review of ACP documents.

The BMA also provides a helpful definition of ‘basic care’ as care primarily intended to keep patients comfortable at the end of life, which includes offering food, liquids, pain relief, hygiene measures and management of distressing symptoms such as nausea and vomiting. It stresses that such care cannot legally be refused in advance, and particularly that it is unacceptable for health professionals to leave patients who lack capacity in pain, whatever their previous wishes.

5.3.1.2 Assessment of mental capacity: a practical guide for doctors and lawyers

This joint publication from the British Medical Association and the Law Society, published in a revised edition in 2010,(19) provides wide ranging advice on assessment of mental capacity in a variety of situations, including a specific section of guidance on assessment of mental capacity to participate in ACP. Also providing useful advice on the process of best interests assessment, this guidance is particularly helpful in interpreting and explaining the requirements of the MCA 2005 with regard to the capacity needed to participate in the different elements of ACP: advance statements of wishes, advance decisions to refuse treatment and Lasting Powers of Attorney.

Commenting on the difficulties often encountered with advance decisions to refuse treatment in terms of ensuring that decisions made in advance are clear and specific enough to ensure correct interpretation and applicability to the intended particular circumstance, the guidance stresses the advisability of involving a healthcare professional such as a GP in the discussion when drawing up such decisions.

5.3.1.3 Withholding and withdrawing life-prolonging medical treatment: guidance for decision making

In the third edition of this guidance,(157) published in 2007, the BMA provided an update on its previous publications taking into account the newly enacted MCA 2005. The guidance explains the statutory provisions for advance care planning in the form of LPAs and advance decisions to refuse treatment, in particular with regard to the interpretation and use of existing decisions in the context of end-of-life care and decisions about life sustaining treatment. It describes the circumstances in which these

decisions may or may not apply, including advice on how professionals can establish whether such decisions are legally binding.

The importance of the use of professional judgment grounded in the statutory requirements in interpreting decisions made in advance is emphasized, with the guidance recommending particular attention to when decisions were made and reviewed; common law cases are cited demonstrating the importance of clear and reliable evidence of the validity and applicability of advance decisions to refuse treatment where they refer to life sustaining treatment.

5.3.2 *The Royal College of Physicians*

Commissioned by the British Geriatrics Society, the Royal College of Physicians (RCP) produced ‘good practice’ guidance specifically for ACP,(172) published in collaboration with the Royal College of General Practitioners, the Royal College of Psychiatrists and the Royal College of Nursing, as well as a number of other bodies and organizations including relevant charities. The guidance provides recommendations for healthcare professionals on the practice and use of ACP, with particular emphasis on its implementation in primary care.

5.3.2.1 Concise guidance to good practice: advance care planning

The authors of this document carried out a systematic review of the existing literature on advance care planning, and followed the Appraisal of Guidelines Research and Evaluation (AGREE)(174) criteria for guideline development. ACP is defined as ‘*a process of discussion between an individual, their care providers, and often those close to them, about future care*’, which may lead to an advance statement, advance decision to refuse treatment or a Lasting Power of Attorney for health and welfare.

Summarizing the important research evidence identified regarding ACP, the RCP also looked at a range of available ACP documents, suggesting that a combination of documents may be most appropriate. Specific recommendations are made in the guidance regarding timing of ACP, the process of discussion, ensuring that ACP is effective, training of healthcare professionals, and implementation of ACP. Particularly aimed towards professionals dealing with older patients and those with conditions such as dementia, the guidance includes a short section dealing with individuals with progressive cognitive impairment.

The RCP specifically highlights the importance of making it clear to patients that while valid and applicable advance refusals of treatment must be respected, the existence of an ACP does not guarantee that wishes will be followed.

Finally, the RCP recommends that ACP should be part of the Quality and Outcomes Framework (QOF) (the structure of annual reward and incentive for good practice in GP surgeries in England) and that it should be considered in the annual care reviews of patients with long term conditions, with GPs also reviewing how many of their patients who die each year have ACPs in place. Action should also be taken to improve recording and sharing of ACPs, with use of electronic records, specific sections of patients' medical records for ACP, and the creation of an ACP register.

5.3.3 *The General Medical Council*

One of the 'duties of a doctor' according to the General Medical Council (GMC) is to, '*respect patients' right to reach decisions with you about their treatment and care.*'(175) Supporting this requirement, the GMC includes in its guidance on end of life care(21) a section of specific advice for doctors on ACP, detailing their legal and professional obligations and giving suggestions as to how and when ACP should best be introduced and used with patients.

5.3.3.1 Treatment and care towards the end of life: good practice in decision making

The GMC recommends the use of ACP with any patients for whom death from their current illness is a foreseeable possibility, and for patients that have a condition that will impair their capacity as it progresses, or those who are otherwise facing a situation in which loss or impairment of capacity is a foreseeable possibility.

The guidance suggests various issues that ACP discussions should cover and advises that these discussions be carried out 'sensitively' and that professionals refer to guidelines on how to approach ACP including those from the RCP, BMA and NHS National End of Life Care Programme.

The GMC requires that ACP is properly recorded and appropriately shared, with doctors encouraging their patients to agree to share decisions with those close to them, other doctors and key health and social care staff. ACPs should also be reviewed and updated whenever a patient's situation or views change.

Where patients wish to make advance requests for treatment, doctors are advised to explain to them that professionals cannot be bound by these but that they will be given weight by those making decisions in the future.

The guidance suggests that where patients wish to make formal advance refusals of treatment or appoint a power of attorney, doctors should give advice on clinical issues but recommend that they obtain independent advice on how to formalize their wishes; however it does not seem to speak specifically of legal advice but instead refers patients and professionals to the website of the Office of the Public Guardian^{ix} and the NHS website on Advance Decisions To Refuse Treatment.^x

When patients have lost capacity, any previous wishes should be taken into account if available when assessing best interests, and legal proxy decision makers or those close to the patient should be consulted. If advance refusals of treatment are in existence, these must be assessed for validity and applicability; the guidance summarizes and refers to the MCA 2005 Code of Practice criteria to determine this. Non binding refusals should still be taken into account as evidence of the person's wishes.

5.3.4 The NHS National End of Life Care Programme

The National End of Life Care Programme (NEoLCP) was set up to develop strategies, building on Department of Health policy, to improve access to high quality care for adults approaching the end of life. Advance care planning is described as an intrinsic part of this programme and several documents have been developed to inform health and social care professionals on ACP.

5.3.4.1 Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff

This guide(176) describes statutory requirements of the MCA 2005 with regard to capacity and care planning, with the interpretations and opinions of a senior expert panel. It gives advice to professionals on timing and context of ACP, outlines professional responsibilities, and provides a list of core competencies for health and social care staff involved in this area of practice. It defines advance care planning as,

^{ix} Website of the Office of the Public Guardian. Available from:
<http://www.justice.gov.uk/about/opg>

^x NHS website for Advance Decisions To Refuse Treatment. Available from:
<http://www.adrt.nhs.uk>

‘A voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record: choices about their care and treatment and / or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses.’

The authors contrast this with ‘care planning’, a wider concept embracing a person centred dialogue to establish needs, preferences and goals of care for people both with and without capacity; in patients who lack capacity, this is to be focused on determining their best interests and making decisions to protect these.

Defining capacity as ‘*the ability to make a decision about a particular issue at the time the decision needs to be made or to give consent to a particular act*’, the guidance stresses that assessing and ‘maximizing’ capacity are essential aspects of ACP. Only those with capacity can participate in ACP, but all must be given every practicable assistance to maximize their capacity, with information provided tailored to their abilities and communication carried out in the way they find easiest.

Describing the ‘formal’ outcomes of ACP under the MCA 2005 as advance statements, advance decisions to refuse treatment, and Lasting Powers of Attorney, the guidance points out that some may not wish to make these decisions or arrangements, and prefer instead to simply name someone who they wish to be consulted if they lose capacity.

5.3.4.2 Advance decisions to refuse treatment: a guide for health and social care professionals

An earlier document⁽¹⁷⁷⁾ this aimed to help health and social care professionals to understand and implement the then new law (MCA 2005) relating specifically to advance decisions to refuse treatment; it does not address other aspects of advance care planning in any detail. The guidance is mainly comprised of a full text copy of the relevant section of the Mental Capacity Act 2005 Code of Practice, with accompanying commentary. It also includes a sample pro forma for advance decisions to refuse treatment, with a list of requirements for advance decisions to refuse life sustaining treatments, a summary flow chart of the process for making best interests decisions, and a checklist based on the MCA 2005 to help professionals assess whether existing advance decisions are legally binding.

The guidance particularly stresses the need for specificity in terms of treatment and circumstances in making advance decisions to refuse treatment, and points out the difficulty in establishing such specificity where a patient is not already diagnosed with the condition. Great care is also advised when making advance decisions in order to avoid unintended adverse consequences. It is pointed out that a refusal intended to avoid burdensome treatment of irreversible symptoms at the end of life could potentially, if not carefully drafted, result in prevention of the simple treatment of reversible illness.

While the MCA 2005 Code of Practice suggests that some people may wish to seek legal advice in drafting advance decisions to refuse treatment, the guidance advises some caution here, emphasizing the fact that lawyers may not be able to provide sufficient information about burdens and effects of treatment or disease.

Finally, commenting on the need for review of advance decisions, the guidance states that since there is no legal requirement for regular review the key issue will be whether decisions are reviewed when the person's circumstances have changed.

5.3.5 The National Institute for Health and Clinical Excellence

In addition to the 'Quality Standards' described above (see section 3.2), NICE guidance on dementia also provides specific reference to use of ACP.

5.3.5.1 Dementia: supporting people with dementia and their carers in health and social care

Focusing on identification, treatment, and care of people with various types of dementia, this clinical guideline recommends the routine use of ACP with patients diagnosed with dementia.(171)

The guideline advises that health and social care professionals should carry out ACP with patients, and their families and carers, while they retain capacity to make decisions for themselves, discussing the use of advance statements, advance decisions to refuse treatment, lasting powers of attorney, and preferred place of care plans. The authors acknowledge the uncomfortable nature of disclosure and discussion of the diagnosis of dementia, both for patients and for healthcare professionals, but stress that such disclosure is essential in order for patients to start to plan for the future; patients need and are entitled to receive information about ACP.

5.4 Key recommendations

The following tables summarize the key recommendations across the various documents discussed in this chapter.

Table 1. Using and interpreting ACP

Key message / recommendation	Supporting body(s)
ACP should be offered routinely in clinical practice / at any time	RCP / NEdLCP
ACP should be initiated in the primary care or outpatient environment, ideally before patients are acutely ill, with referral when specialist knowledge of treatments or prognosis is required	RCP
ACP should be offered to:	
Patients suffering from long term illness and for whom death from this condition is a foreseeable possibility	RCP / GMC
Patients receiving end of life care	RCP / GMC
Patients with cognitive impairment, or a condition likely to result in loss of capacity, early in their disease	RCP / GMC / BMA / NICE
ACP may be useful:	
For patients with strong views on treatment or who wish to maintain control over treatment	BMA
For patients with medical conditions which have predictable treatment options	BMA
At the time of a new diagnosis of a life limiting condition	NEdLCP
Where there is a significant shift in treatment focus	NEdLCP
At assessment of an individual's needs including following multiple hospital admissions	NEdLCP
Doctors should make reasonable efforts to seek out ACPs	RCP
Interpretation of ACPs should involve the use of professional judgement grounded in statutory requirements	BMA
In assessing validity and applicability of ACPs, consideration should be given to whether they are up to date or have been regularly reviewed, as well as to their specificity and clarity	BMA
In patients who lack capacity, non binding previous wishes should be taken into account if available when assessing best interests	GMC
Health and social staff, especially doctors, should be trained in ACP, and there should be promotion of public awareness	RCP

Table 2. The process of making ACPs

Key message / recommendation	Supporting body(s)
Every opportunity should be given to patients to participate in ACP, addressing any reversible issues that might impact capacity and considering the use of clinical vignettes or visual aids	RCP / NEoLCP
Professionals should carry out and record an assessment of capacity or record that there was no reason to doubt capacity	BMA / RCP / GMC / NEoLCP
Individuals should be strongly encouraged to discuss ACP with a doctor, particularly if it involves life sustaining treatment	RCP / BMA
ACP discussions should:	
Be carried out sensitively and tailored to the individual	RCP / GMC
Avoid a rigid or prescriptive 'tick box' approach and instead be carried out as a process, in a stepwise manner	RCP / NEoLCP
Cover patients' wishes, preferences and fears about future care, people they would like involved in decisions, interventions such as CPR, preferred place of care, spiritual needs and wishes for actions after death	GMC
Be tailored to the individual patient, taking into account factors such as age, beliefs, sex, race, and fears about euthanasia which might act as barriers	RCP / GMC
ACP decisions should be clear and specific to ensure applicability and validity when used	BMA / NEoLCP
ACP decisions should be properly recorded and appropriately shared, with efforts made to facilitate recognition of ACPs across healthcare sectors, perhaps with creation of an ACP register	BMA / GMC / RCP / NEoLCP
Suitable ways of recording or storing ACPs include:	
In the patient's GP records	BMA
In the patient's hospital records	BMA
In the form of an ID card or bracelet – patients should be advised to carry something on their person identifying that they have an ACP	BMA / RCP
Using a document including sections for contact details, healthcare preferences, and advance decisions to refuse treatment (compliant with the MCA 2005)	RCP / NEoLCP
ACP should be kept up to date and reviewed regularly or when patients' situation, health, functional ability or views change	BMA / GMC / RCP / NEoLCP

CHAPTER 6

Rationale and plan

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6.1 Introduction

A relatively new concept in the UK, advance care planning is deemed to provide benefits for both patients and healthcare professionals and has been promoted for some time in other countries including the USA, Canada and Australia, where a relatively substantial body of research now exists on ACP. With its association with key themes of modern healthcare including shared decision making, patient choice and personal autonomy, it has proved increasingly popular with healthcare policy makers worldwide. However, while legislative support for ACP now exists in the UK, and a body of professional guidance provides direction on its use with emphasis placed on the primary care environment, there seems to be little research on ACP based in the UK or in primary care.

6.2 Justification for research

Studies have investigated a wide range of themes relating to ACP including communication skills,(103,104) mental capacity,(92,178) patient autonomy,(36) palliative care,(76) legal and policy issues,(83) admission avoidance,(64) dementia care(78) and cultural differences.(136)

Research evidence exists for support of ACP in terms of generally positive attitudes of patients and the general public,(28,31) as well as health and social care professionals.(23,30,34) Evidence also suggests that ACP provides substantial benefits for patients, healthcare professionals and healthcare systems; it gives patients a feeling of control in directing their future care when they may lack the ability to make decisions for themselves,(32) and lightens the burden of decision making for relatives(98) and healthcare professionals(37) as well as potentially reducing the financial burden on the healthcare system by reducing inappropriate hospital admissions and use of expensive unwanted treatments and interventions.(54,64) Furthermore, since most long term care is undertaken in family and community settings, primary care is thought to be the ideal environment for discussions leading to ACP to take place.(85)

These potential benefits underlie current strong support for ACP in UK healthcare policy, with various initiatives to promote its use in practice, as well as its formal introduction into UK law in the Mental Capacity Act 2005. As a result, there is an increasing body of professional guidance now available relating to ACP, of which perhaps the most important is the RCP good practice guidance on ACP published in 2009. This national guideline aims to inform health and social care professionals on

how best to manage ACP in clinical practice and to encourage its routine use, particularly in the primary care environment.

However, given that the vast majority of the previous research on ACP has taken place outside the UK, where different legal systems are in place, findings may not always be directly applicable to clinical practice in the UK. For example, legislation in the USA (Patient Self Determination Act 1990) requires that all patients admitted to care homes be offered ACP, potentially leading to quite different levels of routine use of ACP as well as a different focus on the process. In addition, while the literature does suggest that primary care is an appropriate setting for ACP,(57,85,86,88) there is relatively little research on ACP based in this environment, with again very little from the UK.

While reference is made in UK professional guidance to the use of ACP in primary care, the implementation of these guidelines into clinical practice in this setting is yet to be investigated. It has previously been established that there is often a significant gap between the publication of new research findings and their implementation into clinical practice despite integration into evidence based clinical guidelines, particularly in the primary care environment.(179-181) It might be expected that implementation of ACP in UK primary care would follow a similar trend; the fact that uptake of ACP has been relatively slow in other countries despite numerous initiatives to promote its use,(88,182) with a number of previous studies demonstrating significant and specific practical and psychological barriers to the initiation of ACP,(36,41,91,93) might support this expectation.

Review of the literature therefore would seem to point to a gap in terms of UK based research on the subject of ACP generally as well as a more specific lack of research on this subject based in the primary care environment.

6.3 Purpose of the research

Having identified this apparent gap in the existing research literature, a study was developed to address the need to gain an understanding of current practice in ACP in primary care in the UK, as well as the extent of integration of existing professional guidance into clinical practice. In addition, there seemed to be further scope to explore attitudes of primary care professionals to ACP, as well as to clarify potential barriers to its implementation in practice.

6.4 Concurrent research on ACP in the UK

With this proposal in mind, it was necessary to establish whether any other work was being done in this area concurrently. Following searches of the online databases of National Institute of Health Research (NIHR), the Wellcome Trust and the Medical Research Council (MRC), as well as informal Internet searches, three groups of researchers carrying out major UK based research projects looking at areas including ACP were identified at the time of planning the study. Contact was made with these, and telephone or face to face discussions about the proposal in the light of their work took place with leading researchers in each group.

EVIDEM (Evidence Based Interventions in Dementia, Prof. Claire Goodman et al.) was an NIHR funded programme that aimed to capture a picture of the experience of individuals living with dementia in order to produce useful interventions for patient benefit. The project had a number of relevant themes including examining resources in primary care for follow up of patients after the diagnosis of dementia, interpretation of decision making in dementia and how this fits with the Mental Capacity Act 2005, the impact of the Mental Capacity Act 2005 on current service provision in dementia, and tracking older people in care homes over 4 years looking at care and events.

EQuaDem (Enhancing the Quality of Dementia Care, Prof. Louise Robinson et al.) also funded by NIHR grants, looked at a variety of themes relating to end of life care in dementia and primary care based collaborative care in dementia. Two specific relevant aspects of this body of work were a study looking at how best to implement advance care planning in patients with dementia, and investigation of how improvements could be made in decision making when sending confused patients home from hospital, with a focus on assessment of capacity and best interests in dementia.

A third study, developed as a PhD project (Karen Harrison-Dening), further examined issues relating to ACP use in dementia. This aimed to explore whether ACP was feasible and acceptable for patients with dementia, and whether they were able to generate ideas about the choices they wished to make for their future care, also involving carers in order to establish the levels of agreement between patients and carers and thus the reliability of proxy decision makers in dementia care.

While these studies included elements that looked at the area of ACP in primary care, all were specific to patients with dementia, and focused more on interventions and processes to improve dementia care rather than current practice of ACP in primary care, so there did not seem to be significant overlap with the proposed investigation.

6.5 Definition of terms

For the purposes of this study, the term advance care planning or ACP was taken to refer to a formal process of decision making whereby a capable person, that is one who has the ability to make the relevant decisions, is able to establish choices about healthcare in advance of a potential future state of incapacity.

With regard to the potential outcomes of this process, three elements of ACP were recognized, as defined in the Mental Capacity Act 2005 and the Royal College of Physicians guidance on ACP, each coming into effect only on loss of capacity:

1. Advance statements of wishes, allowing a person to state preferences or wishes for future care to be later considered when assessing 'best interests'.
2. Advance decisions to refuse treatment, being legally binding refusals of treatment, made in advance, which can include refusal of life sustaining treatment.
3. Lasting Powers of Attorney (LPAs) for health and welfare decisions, where a person can appoint someone to make decisions on his behalf with regard to health and welfare.

6.6 Study aims

This study aimed to explore current practice in advance care planning (ACP) in UK primary care, seeking to establish what is good practice in ACP in this setting, and to identify to what extent Royal College of Physicians' guidance on ACP is already integrated into clinical practice.

6.7 Research objectives

1. Investigate awareness and current use of ACP in a sample of UK primary care practitioners.
2. Establish the extent to which general practitioners and other primary care professionals are aware of and utilize existing UK professional guidance on ACP.
3. Identify factors that present barriers to, or facilitate the use of ACP in primary care.
4. Explore the specific perceived needs of UK primary care professionals in carrying out ACP, and suggest how these needs might be addressed.
5. Identify any systems in place to ensure adequate review of existing ACPs, as well as recording or distribution of ACPs such that they will be available when necessary.
6. Identify any potential inequalities relating to the availability and use of ACP in primary care in the UK.

6.8 Choice of methods

The main focus of the proposed research was exploratory, aiming to develop a picture of current practice in ACP in UK primary care, as well as look at the degree to which existing guidance was integrated into clinical practice.

Qualitative methodology is most appropriate to such aims,(183,184) with the potential to gain large amounts of information about the experience of clinicians in primary care with regard to the use of ACP. In this context, semi-structured interviews offer a good balance between reliability and replicability, with standardisation of some questions, and thoroughness and sensitivity in allowing the use of some spontaneous questions, giving greater opportunity to explore individual participants' views and offering them the chance to express themselves;(185,186) this is supported by use of this form of qualitative research interview in other studies exploring views and experiences regarding ACP.(29,32,37,62)

While the study's main aim was to capture the views, experience and practice of clinicians with regard to ACP, the patient perspective has been key to the understanding of this process in previous studies,(32,36,41) so there also clearly needed to be a strong patient focus to the research. Therefore, another part of the study planned to involve members of the general public, balancing the views of clinicians and trying to ensure that important issues relating to the practice of ACP in primary care did not go unrecognized.

Rather than examine individual experiences, a similar semi-structured approach was planned for a focus group, the purpose of which was to open up the views expressed by clinicians to the scrutiny of lay people, allowing detailed examination of important issues raised in the interviews.(187,188) With a number of prepared questions or discussion items based on data emerging from interviews of clinicians, there would also be opportunity for a more discursive process to take place, allowing potential for additional issues to be raised and discussed.

As the aim of the study was exploration of current practice, it was important to test the findings of the interviews and focus group in a broader setting to obtain some degree of validation or confirmation of the importance and reliability of the views expressed and issues raised in these parts of the research. Building on the data from both semi-structured interviews with clinicians and the focus group with lay people, a questionnaire survey of a larger number of primary care professionals was planned to gather quantitative data to potentially add weight to the qualitative findings, while also

allowing an opportunity to explore some issues further, gaining further insight into the use of ACP in primary care.

6.9 Plan of research

The study was therefore developed to comprise three parts. Semi-structured interviews would be carried out with GPs and Old Age Psychiatrists, before a focus group with lay people discussing the findings of the interviews, with questionnaires subsequently sent to a larger group of primary care staff to examine the findings in more detail.

6.9.1 *Individual semi-structured interviews*

Individual interviews, conducted in person at the subject's place of work were planned with a small number of GPs. These aimed to provide qualitative data on current experience of and approaches to ACP, as well as GPs' views on what would be good practice regarding initiation of ACP in primary care. It was proposed that additional interviews might also be carried out with clinicians from another specialist group of professionals, Old Age Psychiatrists. Expected to have particular experience of seeing patients lacking capacity, it was felt that they might offer a useful alternative viewpoint on the use of ACP in primary care.

6.9.2 *Focus group with the general public*

Following the interviews, it was planned that a focus group would be organised with patient advocacy or other lay groups, in order to discuss the issues raised by GPs and other professionals. The aim of this was to ensure that the research retained a strong patient focus, with the opinions of clinicians coming under the scrutiny of lay people. Of particular interest were the views of members of the public on issues such as the importance and usefulness of ACP as well as the timing and circumstances of introduction of ACP to patients.

6.9.3 *Questionnaire survey of primary care professionals*

Picking up on important themes derived from individual interviews with GPs and focus groups with the general public, a questionnaire based survey of a larger number of participants in primary care was proposed, with sections for completion by GPs, practice nurses and practice managers. Intended to provide some quantitative data on important issues identified in the interviews and focus groups, it also included questions

aiming to elicit views on the factors involved in initiation of ACP and produce information regarding the prevalence of ACP in the surveyed practices, as well as seeking to establish to what extent the recommendations of professional guidance on ACP had already been implemented in clinical practice.

6.10 Analysis and dissemination of results

Analysis of results would lead to dissemination of findings by reports, publication and academic presentations nationally as well as through seminars and newsletters to regional and local participants. It was hoped that presentations and seminars would also provide an opportunity to gain useful opinion on the importance of the findings, and to consider ways in which they can be applied to enhance primary care practice in ACP and benefit patients.

6.11 Involvement of lay people in the research design and process

The involvement of members of the general public was planned at two points in the research project, firstly in the design process, and secondly as participants in a focus group during the study.

Advice was sought from the Norfolk Patient and Public Involvement in Research (PPIRes) group on the study design and particularly on drafting of a plain English summary of the proposal which was necessary as part of the application for ethical approval for the study. Subsequent input from PPIRes was also planned for the focus group, with the intention that lay participants would also be sought from other patient advocacy, lay groups and charities.

6.12 Research hypotheses

Given the reported experiences in other countries, it was anticipated that, despite policy in favour of ACP, professional guidance currently in place, and generally positive attitudes towards ACP among patients and healthcare professionals:

1. Professional guidance on ACP would not be effectively integrated into clinical practice in UK primary care.
2. ACP would be initiated infrequently in primary care.
3. Even when initiated, there would be low uptake and completion of ACP.

6.13 Significance of the research

Review of the literature seems to indicate a gap in research in the area of ACP in primary care both in the UK and abroad. Furthermore, while a small number of ongoing studies investigating ACP in the UK were identified, these look specifically at dementia, and do not appear to take an overview of approaches to ACP in primary care. In view of the current drive to promote ACP and encourage initiatives to increase its use, particularly in primary care, it would seem important to investigate current practice in ACP in UK primary care, establishing what is good practice in this area as well as whether current professional guidance is being translated into practice, particularly identifying any perceived problem areas or difficulties in its application.

The outcome of such an investigation would be anticipated to provide a valuable addition to existing research in this area, deepening knowledge of the practice of ACP in UK primary care and potentially helping to develop strategies to promote and enhance its timely and effective initiation in primary care. Particularly applicable to General Practitioners and other UK primary care professionals, the results of this study might also prove to translate more widely especially in terms of relevance in primary care outside the UK.

6.14 Researcher's role

BH is a General Practitioner with interests in medical law and the interface between law and medicine, as well as in Old Age Psychiatry. The development of this study began while BH was an Academic GP Registrar at the University of East Anglia, and continued after completion of his GP specialist training. This work was supported throughout by an academic supervisory team at the University.

CHAPTER 7

Methods

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7.1 Introduction

As set out in the previous chapter, it was decided to employ a mixed methods approach, with qualitative methodology used to allow the collection of rich data on participants' ideas and experiences, but with a quantitative element to test qualitative findings and add reliability and clarity to the qualitative data.

To summarize, the study took place in three stages. Firstly a series of qualitative semi-structured interviews were carried out with GPs and Old Age Psychiatrists. A focus group discussing issues raised during these interviews was then held with members of the public to gain the perspective of lay people on the clinicians' views. Finally, questionnaires were devised, based on data from the first two stages of the study, which were sent to a larger group of primary care professionals to examine the findings in more detail.

7.2 Ethical approval and access to research sites

Ethical approval was sought for the study at an early stage, with review carried out by the Norfolk Research Ethics Committee. The Committee confirmed their favourable opinion on 3rd August 2010, granting permission to carry out interviews, focus groups and questionnaire surveys for the purpose of this research within the local area of East Anglia. Subsequently additional management approval was sought and gained from the following Primary Care Trusts: Norfolk, Great Yarmouth and Waveney, Mid Essex, South Essex, North East Essex, West Essex, South West Essex, Suffolk, and Suffolk Mental Health Partnership Trust.

The Research Ethics Committee was approached on two occasions during the research process for amendments to the agreement, firstly to request an extension of the allocated time for the study (extension approved on 21st May 2012 from end July 2012 to end January 2013), and secondly to allow them the opportunity to review and approve the questionnaires, which had not been developed at the time of initial application (approved 27th June 2012).

It was considered that the potential ethical problems relating to carrying out this work were few, but a number of issues were nevertheless highlighted to the Research Ethics Committee in the application.

It was anticipated that the burden of the research on participants in terms of time would be small. Interviews were planned to last around thirty minutes, and take place in the participant's place of work with the interviewer travelling to that location. The focus

group was planned to last about one and a half hours and to take place at the University of East Anglia, in Norwich, with participants' travel costs reimbursed. Questionnaires were also designed to take a minimum of participant time, and to be as user friendly as possible.

Although unlikely, it was pointed out that it might be possible that some participants, perhaps members of the public in the focus groups, might find aspects of discussion about 'care' or 'end of life care' distressing. Prior to starting interviews and focus group, it was explained to subjects by means of an information sheet that should they find the discussion distressing, they could terminate the conversation at any time and associated data would not be recorded. In a similar way, participants were assured of their right to withdraw from the study at any stage.

In no part of the study were participants asked to disclose identifiable personal information, or information of a confidential nature. However, careful thought was given to protection of personal information at the design stage and throughout the study. Digital recordings of interviews and the focus group were transcribed as soon as possible with only anonymized transcripts subsequently retained for analysis. Questionnaires were returned anonymously and responses transferred to an electronic database with original hard copies destroyed. No personal or patient data were used at any stage, save for the names and addresses of the participants, which were kept on a password protected computer with no other associated data. Where subsequent publications and presentations used direct quotations from participants, these were anonymized and every effort made to ensure that they were not personally identifiable.

Finally, the importance of consent was considered with regard to all participants in the study. Invitations to interviews and the focus group included an information sheet as well as a consent form, with understanding of the information and written consent confirmed before starting the interview or focus group. The questionnaire survey was similarly preceded by an information sheet, but given that the questionnaire was completed anonymously, it simply included a statement to the effect that completion indicated consent to participate.

7.3 Individual semi-structured interviews

7.3.1 *Site and participants selection*

Sites and participants were identified through a combination of sampling methods: convenience, snowballing and purposive. The area of the East of England, specifically the counties of Norfolk, Suffolk and Essex, was chosen due to its familiarity and proximity to BH's places of work, the University of East Anglia, in Norwich, and Lawford Surgery, near Colchester.

All GPs in each of the three counties for whom it was possible to obtain contact details were invited for interview. E-mail invitations were sent directly to GPs in the University GP teaching network, using addresses obtained through the University, while for other GPs they were sent to practice managers at each surgery, using addresses obtained through the research and development departments of each PCT.

A small group of Old Age Psychiatrists was identified through professional contacts, with e-mail addresses obtained with permission of the Trust research and development department from the consultants' secretaries.

A number of GPs who had been interviewed offered to help with recruitment for further interviews and approached other local colleagues to highlight the study. This resulted in several additional participants accepting the invitation to interview.

7.3.2 *Inclusion criteria for interview participants*

The inclusion criteria for interviews were broad. It was decided that participants could be of either sex, and either a registered General Practitioner working in NHS primary care or a Consultant Old Age Psychiatrist working in NHS secondary care. GPs at the practice where BH was working were excluded due to their familiarity with the project and subject matter.

The fact that some GPs might have a greater interest in and exposure to ACP, for example those with an interest in nursing home care, was considered. It was decided that the study would neither specifically target GPs with a special interest which might be relevant to ACP, nor exclude them, but that data on such characteristics of participants would be recorded, and considered if necessary in relation to any substantial variation in exposure to ACP.

7.3.3 Recruitment of interview participants

Recruitment of participants for interviews was extremely difficult. Communication with local research and development departments was complex, and identification of suitable contact details for invitation of participants by this route was very slow. Invitations were sent by e-mail, taking the form of a short paragraph introducing the study, with attachments of the interview information sheet and consent form.ⁱ The interview process continued over the course of one year, with invitations first being sent out in August 2010, and the last interviews taking place in September 2011. All those who accepted the invitation were interviewed (nineteen in total). There was a gap between completion of fifteen interviews with GPs in March 2011 and the interviews which took place with Psychiatrists in September 2011 due to delays in obtaining research and development approval for the research to go ahead at the mental health trust.

7.3.4 Interview process and data collection

An interview guide was developed by BH in consultation with his supervisory team, taking into account the specific aims of the study.ⁱⁱ Designed to facilitate discussion about the key areas of interest for the study, it began with open questions regarding concept and definition of ACP, before continuing to questions about experience and views on ACP. Questions regarding potential problems or ethical issues with ACP were left towards the end of the interview guide, as were those about knowledge of professional guidance on ACP. The guide was adapted after the first nine interviews with GPs, following consideration and discussion of the emerging data with the supervisory team, to include a question asking participants if there was anything that might assist them in carrying out ACP. A slightly modified version of the guide was used for interviews with Old Age Psychiatrists.

Nineteen individual semi structured interviews were carried out with fifteen General Practitioners and four Old Age Psychiatrists. All interviews were carried out by BH. Interviews took place at the participants' place of work, usually in their consulting room or sometimes in a practice meeting room, although one interview was carried out at the participant's home address at his own request. Interviews with the Psychiatrists took

ⁱ A copy of the e-mail invitation, as well as the information sheet and consent form, is included in Appendix 4 (see section A4.1-3).

ⁱⁱ Copies of the interview guides for GPs and Old Age Psychiatrists are included in Appendix 4 (see sections A4.4 and A4.5).

place in a meeting room at the Psychiatric hospital where they all worked. Each interview lasted approximately twenty minutes, ending when all items on the interview guide had been addressed. Interviews were digitally recorded using a portable digital voice recorder, which had previously been tested in several environments to ensure familiarity with working of the device and establish ideal placement of the recorder in order for voices to be sufficiently audible for transcription.

7.3.5 Transcription and analysis of interview data

All interview recordings were transcribed by the interviewer (BH) and some initial thematic analysis carried out as soon as possible after the interview, usually within a few days. While time consuming, personal transcription of the interview by the interviewer was considered preferable to develop greater familiarity with the data. Digital recordings were transferred to a computer, where digital transcription software (Express Scribe) was used which allowed alteration of the speed of play and pausing of the recording. Recordings were first listened to in their entirety before starting transcription, which was carried out in Microsoft Word.

Completed transcripts were then imported into qualitative research analysis software (NVivo 9) for analysis. This program allows highlighting and selection of sections of the transcripts and identification of themes under which relevant sections of the transcripts can then be placed.

The method of qualitative analysis chosen was thematic analysis, which has been described as an accessible form of qualitative data analysis, which is more appropriate to topics where specific issues and themes require exploration. This differs from approaches such as grounded theory and discourse analysis, where there are fewer prior assumptions about the key issues and likely emergent constructs.⁽¹⁸⁹⁾ A flexible tool for analysis of qualitative data, this essentially involves identifying patterns or themes across the whole set of data.

It was understood that when using this form of analysis, themes should reflect something important about the dataset in terms of meaning with respect to the research questions or aims, and usually represent some kind of patterned response across the whole data set. Themes could be identified by either a 'theoretical' approach driven by an existing framework or the researcher's interest in the area, or an 'inductive' or 'bottom up' approach, where the themes are derived more directly from the data. The structure of the interviews as well as the research aims perhaps led to a more

‘theoretical’ approach to identification of themes although effort was made throughout the analysis to ensure that generation of themes was strongly data driven.

Consideration was given to frequency of references with regard to themes, and how prevalent a particular issue should be within the data set in order to be considered a theme. It was felt that while ideally each theme should represent some level of frequency of reference within the data, individual viewpoints were important and that concepts or issues mentioned by only a small number or even a single participant might still be considered a theme if they made what was felt to be a crucial point in relation to the research aims. Similarly, the fact that a large number of participants made reference to a particular issue might not necessarily establish this as a key theme if this did not seem so relevant to the research questions. Relative importance as well as connection within themes was allowed for by the creation of subthemes or theme families, with different but connected items arranged together under a main theme.

This process began immediately after transcription, with potential new themes noted down during transcription and then added to the list of themes within NVivo, and relevant sections of transcript linked to these themes. The NVivo file was reviewed regularly, as more transcripts were added, and all transcripts reread to consider their relevance to new themes.

This continued review process allowed familiarity with the existing themes to be maintained, so that when new interviews started to result in few new themes being identified, this was clearly evident. Where saturation of ideas appeared therefore to have been reached during the last few GP interviews, no further interviews were sought. Similarly, once the four interviews with Psychiatrists were complete it was felt that little would be gained by seeking further participants and this stage of the study was consequently held to be complete.

7.4 Focus group

7.4.1 *Site and participants selection*

In common with the interviews, sites and participants were identified through a combination of convenience, snowballing and purposive methods. The area of the East of England, specifically the counties of Norfolk, Suffolk and Essex, was chosen due to its familiarity and proximity to BH’s places of work, the University of East Anglia in

Norwich and Lawford Surgery near Colchester, with all participants eventually originating from the county of Norfolk.

The focus group aimed to gain the views of members of the general public in relation to the issues discussed in the interviews with clinicians and it was planned to include participants from patient advocacy and other lay groups. Consequently, several relevant charities were identified, the Alzheimer's Society, Dementia UK, Age UK and Carers UK, as well as a group engaged in patient and public involvement in research with links to the University, the Norfolk Patient and Public Involvement in Research group (PPIRes). Local representatives of the four charities were identified through telephone contact with national offices, and subsequent discussion about possible involvement took place by e-mail. PPIRes was approached via e-mail contact with the group's co-ordinator, with subsequent e-mail invitation forwarded to potential focus group participants.

7.4.2 Inclusion criteria for focus group participants

The inclusion criteria for the focus group were broad. It was decided that participants could be of either sex, over the age of twenty one and should be a relative, carer, representative or advocate of a UK healthcare user. Registered medical practitioners and other NHS clinical staff were excluded from participation.

In a similar way to consideration of clinicians participating in the interviews, it was acknowledged that some members of the public would be more interested in this area than others. However, it was felt that for the focus group interested and informed views should be sought, so that there should perhaps be a bias towards participants with an interest in the area of ACP; the groups that were chosen to approach regarding participation in the focus groups reflected this view.

7.4.3 Recruitment of focus group participants

In common with recruitment of clinicians for interviews, identification of members of the general public to take part in a focus group was difficult. Each of the charitable bodies identified, the Alzheimer's Society, Dementia UK, Age UK and Carers UK,

having been contacted initially by telephone were subsequently followed up by e-mail with more information including a focus group information sheet and consent form.ⁱⁱⁱ

Representatives showed initial interest in the project, with several confirming that ACP was something they and their members were keen to be involved in, and while one representative felt that his group was just too busy at the time to engage with the project, the others all made efforts to help with recruitment. Unfortunately these were met with little success in most cases, with few being able to identify active contacts in the chosen area who might be able to participate in a focus group.

However the local outlet of Age UK was able to identify three people expressing interest, following which communication with the Norfolk PPIRes group resulted in the identification of four more contacts, one of whom was in fact an Age UK board member. The group was eventually made up therefore of these four PPIRes contacts with two of the participants identified by Age UK (one was unable to attend). Potential participants were first contacted by e-mail in April 2011, with the focus group taking place in September 2011.

7.4.4 Focus group process and data collection

A guide for the focus group was developed by BH in consultation with the supervisory team.^{iv} This aimed to address the specific issues of interest in terms of the lay people's views, with a focus on consideration of the 'why', 'when', 'where' and 'how' ACP should be approached, and less on issues such as knowledge and understanding of the concept than with the clinicians. Based initially on the questions in the interview guide, it included brief descriptions of some of the interview participants' responses which the group was then asked to discuss.

The focus group was led by BH, as facilitator, with AH (Academic Supervisor) also present and acting as co-facilitator and note taker. The session lasted approximately 1.5 hours, and took place in a small meeting room at the University. The focus group session was digitally recorded, with the same digital recording device used as in the interviews, and this was tested briefly in the room before the focus group started to ensure that voices would be sufficiently audible for transcription. In addition, a secondary recorder in the form of an analogue tape recorder was used as back up, and

ⁱⁱⁱ A copy of the e-mail invitation, as well as the information sheet, consent form, and other pre session information, is included in Appendix 4 (see section A4.6-11).

^{iv} A copy of the focus group guide is included in Appendix 4 (see section A4.12).

AH took brief notes throughout the session. Participants were asked to travel to the University for the focus group, but their travel expenses were paid, and refreshments provided in the meeting room.

7.4.5 Transcription and analysis of focus group data

The focus group recording was transcribed by the facilitator (BH) over the course of the subsequent few days, with some initial thematic analysis being carried out at the same time. The digital recording was transferred to a computer, where digital transcription software (Express Scribe) was used to facilitate transcription in the same way as with the interviews. As before, the recording was first listened to in its entirety, with brief notes of key issues being made, before transcription was carried out in Microsoft Word. The completed transcript was then imported into qualitative research analysis software (NVivo 9) for analysis. Thematic analysis was carried out in the same way as with the interviews, although arguably with a more clearly ‘theoretical’ approach. Since the purpose of the focus group was mainly to gain the views of members of the general public on the issues raised in the interviews, it was felt reasonable to attempt coding into the same themes as the interviews; listening to and transcribing the recording initially seemed to confirm that similar themes could be identified within the focus group data. In fact, it could be said that the focus group was treated for the purposes of analysis in the same way as interviews, with initial coding into existing themes, and creation of new themes where this seemed appropriate. Where new themes were identified, the interview transcripts were also reviewed to see if there was any evidence of these in the interview data.

7.5 Questionnaire survey

7.5.1 Site and participant selection

As with the interviews and focus group, sites and participants were identified through a combination of methods. The area of the East of England, specifically the counties of Norfolk, Suffolk and Essex, was chosen due to its familiarity and proximity to BH’s places of work, the University of East Anglia in Norwich and Lawford Surgery near Colchester. In fact, due to lack of suitable contacts in Suffolk, participants for the survey were only sought in the counties of Norfolk and Essex.

Participants in Essex were identified via contacts at the Essex Education and Quality in Practice (EQUIP) organization made through BH's involvement in a new Primary Care Research Group at Anglia Ruskin University. In Norfolk, participants were identified through the University GP teaching network as well as the Norfolk PCT and Primary Care Research Network via contacts at the University.

7.5.2 Inclusion criteria for questionnaire survey participants

The inclusion criteria for the questionnaire survey were broad. Participants could be of either sex, over the age of 21 and should be a registered General Practitioner, registered GP Specialty Trainee, registered Nurse or Practice Manager working within NHS primary care. Those who had already taken part in the individual interviews were excluded from the survey.

As with the interviews, participants with a specific interest in this area were neither targeted nor excluded. Data on such interests were not sought in the questionnaires.

7.5.3 Recruitment of questionnaire survey participants

In a similar way to the recruitment of participants for individual interviews and the focus group, there were substantial difficulties in terms of numbers responding to the questionnaire survey.

Essex GP practices were targeted first for the survey, with recruitment co-ordinated by Essex EQUIP. An initial e-mail invitation including the questionnaire information sheet, and advertisement in the monthly EQUIP newsletter,^v was followed by hard copies of the questionnaires sent to a group of 24 practices, selected by EQUIP staff on the basis of previous response to questionnaires and other requests for information or participation. Each practice was sent a pack of questionnaires, addressed to the Practice Manager, with one for the Practice Manager, and one for each of the clinical staff including GPs, GP Registrars and Practice Nurses (a total of 258 questionnaires). Subsequently a single e-mail reminder was sent to each Practice Manager, with later follow up to each practice by telephone to ensure that questionnaires had been received and encourage participation; BH either spoke with the Practice Manager or left a message with other practice staff. Practices were first contacted by e-mail invitation on

^v Copies of the e-mail invitation, information sheet and newsletter advertisement are included in Appendix 4 (see sections A4.13-15).

11th July 2012 and it was decided to close this part of the survey due to receipt of no further responses on 28th September 2012.

Following a very low response to the survey in Essex, a different strategy was used in Norfolk, with smaller packs of questionnaires sent to a larger group of practices. Participants were targeted by two means, through the network of GP tutors at the University, and via the PCT to all practices in Norfolk (118 practices). Following initial e-mail invitations, questionnaire packs each containing 1 questionnaire for the practice manager and 3 for other clinical staff, were distributed by hand to all attendees at a GP tutors' meeting and posted to the remaining practices. Practices were first contacted on 20th December 2012, with questionnaires sent out on 8th January 2013. The survey was closed due to no further responses on 26th March 2013.

7.5.4 Development of questionnaire and data collection

Two questionnaires were developed as part of the survey, one for Practice Managers and another for clinical staff.^{vi} Prior to drafting the questionnaires, a number of existing questionnaires were examined, including some provided as attachments to relevant research articles.⁽¹⁹⁰⁾ A significant body of literature on increasing response rate to questionnaires was identified with regard to use of questionnaire surveys in the primary care environment,⁽¹⁹¹⁻¹⁹³⁾ which helped inform the design, including the choice to make paper based questionnaires distributed as hard copies.

Both questionnaires started with a front sheet containing identical background information about ACP and the study, in a 'frequently asked questions' format. This also included a section to identify the participant's professional role and a statement excluding those who had participated in previous parts of the study.

The questionnaire for Practice Managers was intended to gather data about the practices themselves in terms of how they made use of ACP, with the aim of identifying their ability to promote, use and record ACPs, and ideally to gain some estimate of the prevalence of use of ACP within the practices. This questionnaire was kept very brief, but did include a list of suggested Read codes to aid participants in identifying patients coded on their practice databases as having completed ACPs. This was developed with

^{vi} Copies of these questionnaires are available in Appendix 4 (see sections A4.16 and 17).

the aid of two practice managers known to BH as well as the team at EQUIP, in order to try to capture all likely Read codes relevant to use of ACP.

The questionnaire for clinicians focused on confirming or verifying the ideas and opinions expressed in the individual interviews with a larger group of participants. In devising this questionnaire, therefore, the interview transcripts and coded themes were re-examined, with areas considered important then developed into questions. In order to be able to develop a greater understanding of participants' views in the survey, it was decided that most questions would be presented in the form of a Likert-type agreement scale, where participants were asked to indicate their agreement with statements derived from issues raised in the interviews.

A few opportunities were also provided in both questionnaires for participants to express their views on particular points in free text, with a final question on each questionnaire asking for any other comments or thoughts that the participants would like to draw to the attention of the researchers.

Draft questionnaires were discussed with three experienced researchers at UEA in order to establish their suitability. Among a number of changes, this resulted in reordering of the questions such that there was a progression from neutral to more evaluative questions; in a similar way to the process used when carrying out the interviews and focus group, questions about potential problems with ACP were placed later than those about views, experience, and perceived advantages of ACP. In addition, the introductory page was adjusted to include information on why the research was being carried out, and demographic questions, which it was felt might potentially be sensitive or off-putting, were moved to the end of the questionnaires.

Following these discussions, the questionnaires were redrafted and then piloted in two practices, being completed by 5 GPs, 2 Practice Managers, 1 GP Registrar and 1 Practice Nurse. The participants were asked to complete the draft questionnaires along with a further brief question sheet to gain opinions on the questionnaires themselves. As part of this, pilot study participants were also asked to record the length of time that completion of the questionnaire took them. Time for completion was recorded as either 10 or 15 minutes, with no other specific comments about the questionnaire apart from two participants, one a GP and the other a Practice Manager, querying the relevance or necessity of the demographics questions. All questions were completed by participants, with some detailed comments in free text spaces on the Practice Managers' questionnaires, but no free text comments made by the clinicians.

Following this, further discussion was had with the supervisory team, resulting in the decision that demographic information was probably not necessary on the Practice Managers' questionnaire, but that it might potentially be relevant for the clinicians in that it might be found that factors such as age or time in current role affected responses to certain questions; one previous study has shown some differences in views on ACP depending on the sex of family physicians.(23) Questions about age, sex and time in current role were therefore left in the questionnaire for clinicians, but removed from that for Practice Managers.

7.5.5 Questionnaire data extraction and analysis

Data from all the questionnaires were extracted, coded and recorded in Microsoft Excel by BH. Numerical data were then imported into the statistical analysis software SPSS, while free text comments were imported into NVivo for qualitative analysis.

Detailed consideration was given to the method of analysis of the quantitative data obtained with the questionnaires. From discussion with colleagues at the university, including formal advice from a statistician, it was established that some debate exists about data derived from Likert questions in terms of how it should be analyzed. Firstly, there is a question about the definition of Likert scales. Some argue that properly, a Likert scale is a set of questions or statements with agreement scale responses which together describe some characteristic of the participants. These should be analyzed together, using the sum or mean of responses. Stand alone statements with an agreement scale are sometimes distinguished from this and referred to as Likert-type questions. Secondly, there is the question as to whether data derived from questions with Likert or Likert-type responses should be treated as 'ordinal' or 'nominal'; this relates to whether or not the intervals between items on the rating scale are believed to be equally spaced. In analyzing data from the questionnaire survey, it was decided that the main interest was in the responses of the group of participants to individual statements. Although grouped together under question headings such as 'what do you feel are the important practical and ethical problems with ACP?', statements had not been designed as groups to test together specific participant characteristics, so should not be analyzed in this way. Furthermore, since it was not possible to assume that participants perceived the difference between individual items on the rating scales, for example 'strongly agree' and 'agree', to be equally distanced from each other, individual responses should be

treated as 'ordinal', that is, possible to rank in order, but with the intervals between them not defined.

Univariate analysis therefore described responses to individual statements or questions such as *'I am familiar with the concept of ACP'*, in the form of frequencies (percentages) to describe the proportion of respondents giving each response to the given question, with median as a measure of central tendency.

Bivariate analysis was used to try to explore relationships between two aspects of the data, participants' characteristics and responses to individual questions. So, for example, this sought to answer questions such as, *'Did participants' age affect their likelihood to wish to have their own ACP?'* or *'Did the number of years participants had worked in this position affect their confidence in discussing ACP with patients?'* Here, non parametric tests were used, with the Mann-Whitney U test chosen for comparing two groups, such as sex, with the responses to other items in the questionnaire, and Kruskal-Wallis test for more groups, such as age range.

Finally, a number of the questions or statements within the questionnaire for clinicians were thought to address similar 'themes'. In an effort to establish a measure of the general consistency of participants' response to the questionnaire, it seemed relevant to consider the responses to these items using an appropriate measure of internal consistency. Cronbach's alpha was chosen as such a measure,(194,195) and α values were therefore calculated using SPSS for the items believed to represent unified 'themes' within the questionnaire.

CHAPTER 8

Results and analysis

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8.1 Semi-structured interviews

8.1.1 Participant demographic data

Interview participants included fifteen GPs and four Old Age Psychiatrists. They had a mean age of forty five years (ranging from 30 to 63 years), and had been working as a GP or Consultant Psychiatrist for an average of fifteen years (ranging from 2 to 26 years). Twelve of the nineteen interviewed were female (63%).ⁱ

The GPs interviewed described a range of interests and additional qualifications, with eight stating that they had an interest in undergraduate or postgraduate teaching, and one expressing an interest in palliative care.

The GPs' practice list sizes ranged from 6000 to 14000 patients with between three and eleven GPs working in each practice. Twelve of the fifteen practices were involved in either undergraduate or postgraduate medical teaching or training. Most GPs described their practice population as of mixed or average age, and of mixed or middle class in terms of socioeconomic status. Most practices were urban or mixed in terms of area, with three GPs describing their practice as rural or semi-rural. Most had responsibility for patients in at least one nursing home.

The complete demographic data for interview participants are available in Appendix 5 (see section A5.1).

8.1.2 Interview process

Interviews ranged from fifteen to twenty nine minutes in duration, with the recording finishing when all areas of the interview guide (see Appendix 4, section A4.4-5) had been addressed. No problems occurred when carrying out the interviews, with only one brief interruption to an interview, which did not seem to adversely affect the discussion. Recordings were all of good quality with speech clearly audible, and transcription was

ⁱ In terms of age range, it seems likely that this sample was representative of the region with 42% of participants falling within the 45-54 age range, compared with a total of 39% of GPs in this age range across the relevant PCTs in Norfolk, Suffolk and Essex according to 2012 data (the comparable national figure was 34%).

There was a greater representation of females amongst our sample than either the regional (Norfolk, Suffolk and Essex) percentage of female GPs (42%) or the national figure (47%).

These data were obtained from the Health and Social Care Information Centre website, available from: <http://www.hscic.gov.uk>

therefore possible without difficulty. No participants made any requests for transcript review or data withdrawal.

8.1.3 Analysis of data

Following transcription of the recordings, and initial familiarisation with the data, thematic content analysis resulted in the following key themes being established:

- General reaction to discussion
- Concept of ACP
- Experience of ACP
- Familiarity with guidance
- Familiarity with legal status
- Support for ACP
- Advantages of ACP
- Barriers to ACP
- Carrying out ACP
- Problems with ACP
- Ethical issues
- Ideas for improvement

The following pages describe these key themes in detail, illustrated with relevant quotations from interview transcripts. While generally, in accordance with accepted qualitative methodology, counting of comments was not considered useful, occasionally, where relevant, the number of referenced comments on a particular issue is given, alongside the number of sources (individuals) who made these comments.

8.1.3.1 *General reaction of participants to discussion of ACP*

Each interview started with a question about knowledge, *‘What do you understand by the term advance care planning or ‘ACP’?* Participants had not been forewarned of this question, with no explanation of the concept in the interview information sheet, and most (43 references from 15 sources) responded with some caution initially. Answers to this in particular but also to other questions about knowledge, for example discussion of professional guidance on ACP, tended to include frequent pauses, guarded statements or further queries, with sometimes a sense that participants were afraid of criticism or of being ‘caught out’:

‘Um... to me, advance care planning, or advance care plans, probably is... I don’t know whether this is what you mean... but for me...’ (IN-1).

‘Well... I didn’t look it up or anything...’ (IN-5).

Similar uncertainty and unwillingness to commit to a definite response was evident in discussion of legal status of ACP, with some suggestion of apprehensiveness on the part of participants about their legal obligations regarding ACP.

‘But also, you know, with the legal implications, I think that would mean we’d have to take responsibility for another, you know... We’d need to really know the ins and outs of the legal... (IN-6).

However, despite this, all participants reacted positively to the interviews, engaging with questions and giving full and thoughtful responses; most interviews appeared to flow comfortably, with the feeling of a relaxed discussion between professionals developing either from the outset or within a few minutes.

Throughout the interviews there seemed to be an overall positive reaction to the concept of ACP, with positive use of language and supportive comments. Participants made frequent use of first person pronouns, ‘I’, ‘we’ and ‘us’, with expression of their hopes and wishes with regard to the use of ACP.

‘I, for me, personally... I would welcome this... For me it’s quite an honour’ (IN-9).

Many clearly demonstrated their interest in the discussion, thinking carefully about the issues involved and trying to explain and understand their views, as well as showing evidence of empathy for patients and understanding of what it might be like to be in the position of those making ACPs:

‘I think it is good for us as clinicians... because then we have an understanding of what the patient wants, and something to work towards... But more importantly for patients, it helps them feel... yes, more in control at a time that you’re actually quite out of control...’ (IN-1).

A few participants did express more negative reaction to ACP in the interviews. Where this occurred, however, it tended to focus on concern for their patients and awareness of potential ethical problems. One GP, for example, recounted an episode where a couple’s advance decisions to refuse treatment made her feel uncomfortable, while one of the Psychiatrists worried about a perceived potential overlap with assisted suicide and euthanasia:

‘And they seemed really... too extreme for me... And I felt quite caught in the middle of it...’ (IN-2).

‘Because there’s this fear of people not wanting to be a burden. I think that’s quite concerning. You know, that people feel they’re not valued... And the way to not be a burden is not to exist.’ (ISMH-17).

Finally two GPs voiced considerable frustration at the quality of ACP carried out and lack of ACP use in general both from the point of view of professionals and patients:

‘And it’s done so inadequately, you know... I just think it’s generally done very poorly...’ (IN-3).

‘What surprises me is how few people have got them... It’s very selfish!’ (IS-7).

8.1.3.2 *Concept of ACP*

Participants were unfamiliar with the term advance care planning and hesitant in committing themselves to defining it, with some quite open about their lack of knowledge about this:

‘Not much really... I’m not very clear on the definition of it I have to say.’ (ISWE-10).

‘I haven’t heard of it used as an entity, I just know what it might mean...’ (IN-8).

However, most subsequently provided further description of their understanding of what ACP might involve which suggested a relatively firm grasp of the concept. So, for example, the GP above, who had not heard the term used, suggested:

‘What I think it might mean is that if someone is terminally ill, or... has a chronic illness, that you actually put plans in place to ensure that their care is kind of seamless... that we all know what the patient’s wishes are... in other words that you actually know what the patient wants.’ (IN-8).

More specifically, participants showed evidence of an understanding that ACP is a process of discussion with patients who still have capacity to make decisions, that involves planning for future care, anticipating a time when they may not be able to make decisions for themselves:

‘Really it’s about... talking to patients about what their long term thoughts are for a condition.’ (IN-3).

‘People when they are in a state of mind where they are competent to make decisions, make a plan for their future care, when they’re perhaps no longer able to make that decision themselves...’ (IN-2).

In addition, there seemed to be a feeling that there was a particularly close association with end of life care, and in this context that ACP might often involve decisions about resuscitation, use of treatments such as antibiotics and fluids, and identifying the particular place where a person should be cared for at the end of life:

‘Thinking about those, usually in the context of terminal illness, who are going to die in the foreseeable future.’ (INEE-12).

‘Okay so what do I want to happen towards the end of my life? Do I want to go into hospital or not? Who do I want to look after me? Where do I want to die?’ (IN-1).

8.1.3.3 *Experience of ACP*

Most participants stated that they had little experience of making or using ACPs with patients, with only twelve of the nineteen interviewed mentioning any experience at all. While some did recall having patients give them documents detailing their future wishes, which were then added to their records, they tended not to have had any personal involvement in drafting the documents or in any related discussions:

‘It’s not uncommon on our notes to see ‘has made a living will’ but, um, I must say I’ve probably only in the six years I’ve been here, only been asked to talk about it with someone perhaps three or four times... It’s not very common.’ (IN-2).

‘Not really... Um, I had one patient, who was a previously qualified nurse... who had given me a copy of hers, and I agreed to file it in the records... But no, they are very infrequent.’ (INEE-15).

Participants were aware of a range of ways in which ACPs might be made, from verbal statements by patients to their families or health professionals, to formal written documents. Some had seen or used forms or documents for ACP, and most of the GPs had some method of recording patients’ wishes in an appropriate manner on their computer record.

Participants’ descriptions of their experiences of ACP generally seemed to centre around a small number of patients approaching them with ACPs often already made, as well as the occasional suggestion of ACP by the professionals themselves in palliative or end of life care situations, and this impression was shared by one of the GPs:

Certainly, there’s two groups of people... we get a lot of people that retire up to here, and I think that’s when a lot of people start thinking about the future, and they’re making all sorts of plans, wills, and they’ve often sold a house, and they’re thinking about disposable income and I think that’s a time when people often do start thinking about it... And I think the other time... at which a doctor might initiate it is if someone is moving into a terminal stage of illness, and then I would sometimes talk with someone about what they are wanting, and what they are anticipating and how we can best help them get what they want in terms of their mode of dying.’ (IN-2).

Six participants did have some experience with powers of attorney but gave the impression that this tended to be more in the context of confirming patients’ capacity to make them rather than discussing or advising on them:

‘We have signed a few documents in advance about power of attorneys... When they’ve wanted confirmation that the patient is aware of what they’re doing and what it implies, then I’ve signed the legal documents that have come through...’ (INEE-12)

There were some exceptions, with two GPs feeling that they had more experience in this area:

‘I think I’ve got quite a lot actually.’ (IN-3)

‘I’ve come across it... yes, I have... A lot actually because I work in a very middle class area.’ (IN-9)

However, Old Age Psychiatrists also had very mixed experience, with only two of the four interviewed describing discussion of ACP with patients with any frequency:

‘I must admit, not many of my patients do use advance directives. Lasting Powers of Attorney, yes, this is commonly happening, that people are asking about it, and I’m giving advice about it.’ (ISMH-16).

‘I have no personal or practical experience of it, except for occasionally where people have said they don’t want resuscitation or something. I’ve been asked to be the person who can say where the person has the capacity to sign Lasting Powers of Attorney, but that’s about the end of it really.’ (ISMH-17).

8.1.3.4 *Familiarity with guidance*

Participants lacked familiarity with professional guidance on ACP, with most being quite open about the fact that they had not read anything recently relating to ACP, and sometimes a little apologetic, with some suggesting that they felt a need to ‘get up to date’ in this area:

‘Not really no... and it’s funny because I was thinking about this when I remembered you were coming, and I was out doing a visit, and I thought, “Oh bother I was going to do some reading up over the weekend and look all knowledgeable!”’ (IN-2).

Some clinicians did mention sources of guidance on ACP such as the GMC and BMA, and a number were aware of or had been involved in using the Gold Standards Framework programme; none seemed to be aware of the RCP guidance on ACP or of the NHS End of Life Care Programme however. Where participants had come across guidance, they tended to be vague about the content, with several suggesting that perhaps these documents might not be particularly interesting, pointing out the difficulty experienced by clinicians now expected to keep up to date with so many of these kinds of documents:

‘I think, well the GMC brought out something recently didn’t they about end of life care or advance care planning, and I’ve probably got that up on my bookshelf! But I did read it!! The thing is that when a lot of it is sort of relatively, to me, relatively dry stuff... it

goes in, I know what it's all about, but it may not be something that's sort of top of my interest list...' (IN-1).

'Like a lot of this stuff, it's in one ear and out the other... as the next guideline and the next something comes along... You know, it just... unless you're using it every day, it's very difficult to keep... These are the NICE guidelines that I'm yet to read... um, those are the one's that I have read. [Shows two piles of documents].' (IS-7).

A few participants also mentioned other sources of information or knowledge on ACP such as radio programmes or journal articles; one GP had attended a local teaching session where ACP was discussed in the context of end of life care, which seemed to have inspired an interest in this for him:

'I went to an end of life lecture at the John Innes and I think that really started it for me... it was a kind of catalyst for thinking about it...' (IN-3).

8.1.3.5 *Familiarity with legal status*

Clinicians were aware of a number of terms relating to ACP, with various mentions of 'advance directives', 'Enduring Powers of Attorney', 'Lasting Powers of Attorney', and 'living wills' but tended to feel somewhat unsure about the meanings of these and which were in current usage:

'Advance directives I've heard of, which basically, to my knowledge, was what people talk of as a "living will."' (IN-8).

'There's an advance care directive, and there's some... what used to be called a living will, but I think that's a lay term and not, no longer what... and there's also lasting power of attorney.' (INEE-13).

There were no mentions of 'advance decisions to refuse treatment' or 'advance statements', although when these terms were introduced by the interviewer, participants often recognized them.

One GP mentioned the Mental Capacity Act 2005 unprompted, and a few knew that this gives provision for ACP; some participants showed an awareness of the fact that terminology had changed recently, albeit without committing themselves to what the new terms might be:

'Advance directives... But it's changed hasn't it? The terms have changed in recent times?' (ISMH-17).

Many clinicians showed more familiarity with Lasting Powers of Attorney. However, this tended to be in the context of financial planning, with less awareness of the option of attorneys with responsibility for health and welfare:

‘It tends to cover mostly the financial area, and it doesn’t really cover access to medical records and confidentiality, so if somebody’s got a power of attorney, then yes, I will listen to them, but that doesn’t automatically give me a right to disclose medical information...’ (INEE-15).

For some there seemed to exist considerable confusion relating to the old term ‘Enduring Power of Attorney’, how attorneys are appointed and the ability of such attorneys to make decisions about healthcare matters:

‘I didn’t realize that it excluded them before, I thought that um... an Enduring Power of Attorney was something that was enacted by the court when people reached the stage where they couldn’t make decisions for themselves, and I thought it meant... for consent to treatment as well as for financial affairs...’ (IN-8).

There was sometimes a feeling of apprehension among participants with regard to the legal obligations involved in ACP, with some declaring themselves very unsure:

‘Probably not, I mainly just sort of blunder forward!’ (IN-3).

However, professionals were aware that ACP could only take place if the person had the capacity, and there was a recognition that this would depend on the decisions to be made, with an ACP potentially being made up of a number of decisions for which capacity assessment might be necessary:

‘You would have to be careful that every decision they made was one that they had the capacity to make.’ (IN-1).

Participants generally had a good grasp of how to assess capacity, mentioning criteria listed in the MCA 2005 test. Acknowledging that this assessment for ACP might be difficult, several suggested that they would carry out a Mini Mental State Examination(196) or similar cognitive test to help inform their decision,ⁱ and that if they were unsure or in difficulty they would consider referring the person to an Old Age Psychiatrist for further assessment:

‘If it’s gone beyond the stage of them having capacity to make the decision, then I’d involve the psycho geriatricians to do a more formal assessment and advise on how to protect their interests.’ (IN-8).

Several of the Old Age Psychiatrists interviewed seemed familiar with this kind of referral, and one expressed his approval of this approach:

ⁱ The Mini Mental State Examination (MMSE) is a commonly used screening tool for cognitive impairment, developed by Folstein et al. in 1975.

‘My own feeling is that we as Psychiatrists have had more training... on assessment of capacity. So, I’m quite happy for GPs to ask my advice for the very tricky ones. I’d much rather it was done that way...’ (ISMH-16).

Participants seemed to have a good appreciation of the legally binding nature of decisions made by patients in advance as well as a clear sense of the need to establish that the person involved had the necessary capacity when the decision was made:

‘I don’t know in a concrete way, but I think you have to pretty much follow them... if you’re certain they had the capacity to do it at the time...’ (IN-5).

‘Yes, and then it becomes an assault, just as it would be if the person was competent to refuse.’ (INEE-13).

It was also evident from the comments of some participants that they had a perception of advance care planning as not always being clear cut, that sometimes decisions might need to be re-evaluated in the light of subsequent events, and that decisions made in advance might need to be interpreted in the context of the patient’s best interests:

‘If somebody doesn’t quite understand that just going into hospital for, not a major treatment, but you know they will be back out without any complications... just the lack of understanding of what that involves, might be something where you may consider overriding that...’ (ISWE-11).

‘And we’d be guided by, I suppose at the end of the day, what’s in the best interests of the patients, and what the power of attorney, or carers, or kin, feel is appropriate... So it’s more discussion, than it is sort of black and white, I would say.’ (INEE-15).

However, some still had concerns about the legal implications of ACP and their knowledge of the ‘ins and outs’, suggesting that they might not have the ability to ensure ACPs were made effectively or in fact to interpret ACPs that were already made:

‘And I don’t think I would be very good at giving advice. I think I would say, ‘Go and talk to a lawyer’, because to be sure that they’d got it, if they really wanted something watertight.’ (INEE-13)

‘I think sometimes you’re not sure... sometimes you’re not sure about the legality of them are you... Because it has to be, sort of, you know, in a certain form, doesn’t it, to be sort of valid in certain circumstances...’ (ISMH-17).

8.1.3.6 *Support for ACP*

It was clear from the interviews that participants were in favour of ACP, feeling that it was something important and that it should be offered more frequently to patients:

‘Well I’ve got to say I’m a bit of a convert to it...’ (IN-3)

‘I think it is important and we ought be doing it more.’ (INEE-13)

‘I think, that’s probably something that we should do more of anyway... in the absence of kind of having an advance care plan that’s kind of an official document, it almost it just needs to be just part of what we do with patients...’ (IN-1)

Even one GP who felt the subject of ACP to be rather dry recognized its importance and suggested some personal commitment to make more use of the process:

‘Because, I mean, it’s not the most exciting topic in the world... I mean maybe to some people it is! But actually it’s very important... so I think it’s something that I need to look at a bit more.’ (ISWE-10).

In fact, feeling existed that perhaps ACP should be something that everyone might consider, regardless of health status:

‘It probably would be appropriate for everyone to try and think about these things before it’s too late!’ (ISMH-18)

For some, this extended to a more personal interest in having an ACP, with one of the Psychiatrists having already made a power of attorney, and several GPs stating their intention to make their own ACPs, or expressing wishes about how they might be cared for in the future:

‘And I think I probably... probably after this interview that’s the first thing I’m going to go and do!’ (IS-7)

8.1.3.7 *Advantages of ACP*

Participants were clear about the advantages of ACP, sharing a view that ACP is of benefit to patients, their families and carers, and to healthcare professionals. They felt that ACP could provide a clear guide to patients’ wishes for professionals to follow, facilitating decision making, and perhaps also avoiding some of the conflict which may occur between professionals and families caring for patients who lack capacity:

‘You know what you’re doing is... not just your view of what is in the patient’s best interests, but actually what the patient was wishing, so there’s a clear pathway there for you to go down. And dealing with the family... I think it is really helpful to have that extra solid evidence of why you’re doing what you’re doing, and that it is what someone wanted...’ (IN-2).

ACPs might also provide particular benefit for families and carers, in reducing an actual or perceived burden of decision making placed on them, particularly when doctors had to ask for their views in best interests decisions:

‘I think it helps the family to know what they want, because the onus on the family to make a decision about withdrawing treatment or not providing treatment... is much more difficult if you haven’t had those discussions before, and yet they’re being asked to make that kind of decision with the doctor.’ (IN-8).

‘And also it probably takes some of the stress possibly off the relatives, if they know exactly that that is your wish. Because quite often they don’t know, and they’re left with some very, very difficult decisions, the relatives, at a later date.’ (ISMH-19).

More generally, the existence of an ACP might give both doctors and relatives a feeling of reassurance that they had as far as possible acted in accordance with the patient’s wishes:

‘But I think everyone felt they had done... that they had done what they could.’ (IN-5).

For patients themselves, many participants believed that ‘control’ was a key benefit, with ACP giving them control over their future care which they would otherwise lose when they lost capacity:

‘So... I think for them, having a choice is the most important thing. So they need to have that feeling of being in control and make their own choice in terms of treatment, now and later on.’ (IN-9).

One of the Psychiatrists particularly stressed the importance of this control, which he saw as a right of patients:

‘I guess the major benefits are that patients have more control over their own healthcare and their own finances and their own outcomes. And that is empowering, and it’s right as individuals that we should be able to control what happens to us.’ (ISMH-16).

Further considering patients’ own experiences of healthcare, one GP explained why being able to retain control over future treatment might be of particular value:

‘Oh I think people are naturally very afraid indeed, people who have the imagination, and want to think ahead, it’s a frightening thought to be subjected to treatment, life prolonging treatment, perhaps of an invasive kind, that they don’t want to have, so perhaps having some measure of control over it is important...’ (INEE-13).

Finally, there was some feeling among participants that ACP might, in avoiding unwanted and unnecessary admissions, treatments or interventions, have the potential to save healthcare costs:

‘Just from the sort of healthcare costs, it probably does help that if you know they don’t want this that and the other... because a trip to the hospital in someone’s final days does actually add a lot of money and it might not actually give any increased quality of life for them... So for the wider health economy it probably is a good thing.’ (ISWE-11).

8.1.3.8 *Barriers to ACP*

Participants were well aware of potential barriers to ACP, (with 151 references in the 19 sources), suggesting a variety of factors which might present obstruction to the initiation or carrying out of ACP with patients, particularly focusing on issues relating to healthcare professionals themselves.

It was suggested that doctors might feel uncomfortable bringing up the subject of ACP and discussing it with patients. Some related this discomfort to what they called the ‘medical model’, with the idea that doctors are trained to cure and do not therefore relate easily to discussions about end of life issues:

‘No, I think they are very uncomfortable with the whole aspect, and I don’t know why... I think, like the clinicians at the hospital, we’ve still got a little bit caught up in this desperate... that we’re always treating people to get better...’ (IN-3).

‘I think the main difficulty, is cultural. That it is not part of accepted practice at the moment, to discuss end of life issues, until you reach the terminal phase.’ (INEE-15).

Similar factors might act as barriers from the point of view of patients, with a cultural reluctance to discuss end of life issues, and a persistent belief in the potential of ‘cure’. Several GPs also pointed to a perceived reluctance of some consultant colleagues to be open about prognosis with their patients, which they felt might exacerbate this problem:

‘Because some people are still hoping that I’ll prescribe a drug that will make them as they were.’ (INEE-14).

‘Look I think one of the issues is that terminal illness often comes up as a surprise to the individual... and advance directives are not high up on their radar... One of the main problems that I’ve come across, is really with the oncologists not being as straightforward as they might with the eventual outcome.’ (INEE-15).

There also existed a feeling that professionals might sometimes find ACPs put them in a difficult position where they did not necessarily agree with the decisions that had been made by their patients:

‘I think sometimes there can be some conflict... and I’m thinking specifically about this lady... who isn’t actually terminal but is still very adamant that she doesn’t want antibiotics for certain things... And I’ve already said to her that I would find that very difficult... to follow.’ (IN-5)

One GP felt that doctors might also find it difficult to relinquish control to their patients, allowing them the ability to make decisions about future care, while another considered how ACP discussions might cause professionals to reflect on their own mortality:

‘I think, as a doctor, it’s always difficult to leave the control to the patient... I don’t think that’s the way we are trained. We are trained to be in control.’ (IN-9).

‘I think it’s because... when you talk about other people’s mortality, you’ve... people reflect it on themselves... It’s very difficult not to... The fact is that we’re all going to die one day, and... that’s not a nice thought...’ (IS-7).

From a more practical point of view, a number of GPs worried about the time involved in carrying out ACP, with several complaining that it was ‘just one more thing’ added to an already heavy workload:

‘Finding time to address it, because it’s not something that you can just fit in the last minute of a consultation.’ (INEE-14).

‘It’s just another thing isn’t it, just one more thing...’ (INEE-13).

Some expressed concerns about upsetting patients and families or seeming morbid in bringing up the subject of ACP, although one GP felt that in actual fact patients were probably quite open to the discussion:

‘So I suppose, really the problems are that you can actually cause more harm by saying... by drawing it to their attention... And by, you know... saying, “you need to plan for the future”.’ (IN-6).

‘Raising the question is delicate, and so that’s one problem, but I think often actually people are surprisingly happy to be asked...’ (INEE-13).

When asked about their thoughts on inequalities with regard to availability of ACP to patients, most were clear that such inequalities existed, with a range of barriers suggested which might provide explanations for this. In particular, it was felt that there was a lack of public knowledge on ACP, with minimal publicity on the subject and most people simply not being aware that ACP was available. Cultural, educational and financial barriers were mentioned, with a feeling that ACP was an activity mainly carried out by middle class and educated patients. One GP admitted that he was more likely to approach ACP with patients with whom he got on personally or felt it easier to talk to:

‘I think it’s, I don’t think people generally know much about it.’ (ISMH-16).

‘I’ve never seen a programme on it... I’ve never heard a debate on the radio about it...’ (IS-7).

‘I’m sure that people who are more articulate and educated are more likely to do it.’ (ISMH-18).

‘Probably more people who you can talk to and get on with are probably more likely to get this...’ (ISWE-11).

‘I come across people who can barely read and write... So... if you say to them, ‘Write it down’, they’d be horrified.’ (ISMH-18).

‘You probably have to involve a solicitor... presumably that’s going to cost money... So that’s not necessarily going to be... you know, financially available for them at the moment...’ (IN-6).

8.1.3.9 *Carrying out ACP*

Some discussion took place about who tended to start the process of ACP, with patients themselves, relatives, nurses, GPs and Old Age Psychiatrists all mentioned: there seemed to be a mixture of approaches. One GP suggested:

‘I think we’re not always that great as doctors at initiating things like that... I suppose, patients can initiate these things themselves but I’m not sure how many really do...’ (IN-1).

However, there was also a strong feeling, from both the GPs and the Psychiatrists interviewed, that primary care was a very suitable environment for ACP, with GPs particularly well placed to offer ACP and carry it out, due to their relationship with and knowledge of their patients and the opportunities for continuity of care:

‘We definitely should be part of it. I’ve worked in this practice for six years, so lots of patients I know quite well... So if you would ask me what would be good for that person... I would probably know, because I know their ideas, what sort of ideas they have got about treatment, what their religious belief is, I often know...’ (IN-9).

‘Well, you know, my perspective on the GPs... is that they are the professionals that are there from the very beginning, well, before the patient became ill, to the very end. They have this amazing position of continuity of care, and of being a huge source of support. So that’s why I think they should play an important role if they can.’ (ISMH-16).

Most participants had suggestions as to situations or specific conditions where ACP would be appropriate or useful or which might prompt patients, carers or professionals to consider ACP. A number mentioned patients with long term, chronic or life limiting health problems, or those who had recently experienced some life changing event, such as the death or illness of a friend or relative, or even simply retirement and moving home. Specific conditions or situations mentioned by several participants included cancer and palliative care, heart failure, stroke, Multiple Sclerosis, Motor Neurone Disease and Chronic Obstructive Pulmonary Disease.

Dementia or memory problems were referred to as conditions relevant to ACP in all nineteen interviews, with most of these mentions unprompted. For many, this seemed to

be felt to be a particularly appropriate, though potentially also especially difficult, condition in which to use ACP, due to the likelihood of such patients to suffer future loss of capacity:

‘I can think of people that maybe are getting to early dementia who you would think yes, obviously because they may lose capacity in the future.’ (IN-1).

One area of difficulty mentioned, particularly with regard to patients with memory problems, but also relevant to other situations, was timing of ACP. Many participants commented on how hard it might be to identify ‘the right time’ to discuss ACP with their patients, balancing between a perceived risk of upsetting them by asking ‘too early’ and leaving it until the person had lost the capacity to participate:

‘I think this is where the discussion needs to come in fairly early on... where people are likely to have a reasonable functional level... sad to say I don’t think we’re very good at that, especially in Alzheimer’s it’s often left until quite late in the day, by which time people’s cognitive ability is actually quite damaged...’ (IN-3).

8.1.3.10 *Problems with ACP*

Participants were able to identify a large number of potential problems with the use of ACP in clinical practice.

Some worried about patients making unnecessary or inappropriate ACPs without full understanding of the consequences and were concerned about the potential for patients to make their own ACPs without necessarily seeking medical advice. One GP described a situation where a patient had made an ACP refusing future treatment based on a mistaken understanding of her condition and prognosis:

‘She’d basically panicked and thought that therefore she was dying... And so when we had the chat I said that, you know, ‘they’re planning to cure it’ do you really mean that if you’ve got pneumonia you don’t want antibiotics because that could be something completely treatable and have nothing to do with your cancer at all...’ (IN-5).

Some also pointed out that ACP was simply not appropriate for all patients, with one consequently requesting specifically that ACP not be made part of QOF (the Quality and Outcomes Framework):

‘I don’t want it as a QOF! Okay. So not QOF... Some people just don’t want to think in those terms, and you’ve got to accept that...’ (INEE-14)

Several participants commented on the possibility of problems occurring with families relating to ACPs, with some concerned that difficulties could arise where families disagreed with what patients had decided in ACPs, and describing experience of where

ACP rather than relieving the burden on families, actually compounded it:

‘Several times I’ve come across patients who say they don’t want to die in hospital... and the relatives do their best to stop them dying in hospital, almost to the point where they can’t cope properly...’ (IS-4).

A large number of comments (24 references from 11 sources) related to participants’ concerns about the likelihood of ACPs actually being followed. A number pointed out that sometimes it just was not possible to follow people’s wishes exactly, with one likening ACPs to birth plans, which he felt could only be viewed as a description of an ideal scenario, suggesting that there might even be dangers in following ACPs too strictly:

‘Some things, people were able to accommodate, other things you... you know, as time went on you just couldn’t...’ (IN-5).

‘A birth plan is an aspiration. And when it comes to advance care planning... I think it should be borne in mind that this is an aspiration, and what happens is not going to be that... it’s a guideline... this is what we’d like in a perfect world... So I think the danger is that if you... with advance care planning... is that you can stick to it too rigidly... especially in palliative medicine, you’ve got to be very fluid in your approach to it...’ (IS-4).

One of the Psychiatrists raised a specific concern about healthcare staff who might not fully understand the meaning of an ACP, perhaps resulting in a person receiving substandard care or being denied care inappropriately:

‘I can think of a particular example, somebody who was on a medical ward, was quite unwell, and had written an advance directive to say that she didn’t want to be resuscitated. And the staff were quite anxious about giving her any sort of treatment at all! You know, they thought maybe they just ought to leave her alone. Which obviously was a misunderstanding, but you know, obviously you need to be careful, that your wishes are either not misinterpreted, or you know, taken out of context...’ (ISMH-18).

Relating to this it was acknowledged that it could be extremely difficult to draft ACPs with any certainty that they would be interpreted as intended, with many clinicians highlighting a complex balance between making a plan specific enough to cover issues of particular concern to the person, while still covering a range of possible situations:

‘As with most things in medicine, they tend to be quite grey. So I guess that the more general it is, the more open to interpretation it is in that situation... It could also be very specific and therefore often when something is very specific... the clinical situation

doesn't relate to that and you can find lots of other ways around... interpretations of it... I would think in practice that would be the situation...' (ISWE-10).

The problem most frequently mentioned by participants (with 33 references from 11 sources) was that of availability of completed ACPs, with it being pointed out that while ACP discussions may have taken place, if decisions are not documented and available at the time that they are needed, it is unlikely that healthcare professionals will be aware of and able to follow them. In particular some highlighted difficulties in communication with out of hours and emergency healthcare staff, and in making them aware of the existence of ACPs, with one GP involved in out of hours work expressing considerable frustration at the current state of affairs:

'People say well this has been thought and discussed with the GP – well unless it's been written down, it doesn't matter a jot on a Sunday afternoon...' (IN-3).

8.1.3.11 *Ethical issues*

Participants seemed to have a keen sense of the various potential ethical issues relating to the use of ACP.

With some discussion having taken place in other interviews regarding the possibility that ACP use might save healthcare costs, one GP raised concerns about the ethics of this as a potential driver for ACP:

'I think that the question is why someone is going to be making these wills... If I was the person advising them, why am I advising them... is it because I want to save my budget, for this consortium or the NHS?' (ISWE-11).

Aware that changing an ACP would require the patient to have capacity, some worried that without regular review of ACP, patients might change their mind but not have the opportunity to make changes to their ACP. Having experienced patients dramatically changing their views about treatment, many (22 references from 13 sources) felt strongly that prediction of one's future wishes for the purposes of ACP was extremely difficult:

'I think when you experience something, it's very different to what you think you might be going to experience. And I think that for a lot of people in all sorts of health related issues, how they think they're going to react is different to how they actually do react. And there are plenty of people I've seen who've said 'if it's cancer I don't want any treatment' and then they have, you know, the full works...' (IN-2).

For several participants, these ideas led to more philosophical discussion, with questions raised as to whether current and future ‘selves’ were the same ‘person’. One of the Psychiatrists, for example, commented:

‘It’s sort of assumed that we’re one individual with one set of beliefs and attitudes that are immutable, and that’s quite a nice thought... but actually, I’m a very different [me] to the 18 year old [me] and I’ll be a very different one when I’m seventy. And so that needs to be taken into account.’ (ISMH-16).

Expressing a similar view, one GP felt that perhaps it might be unfair for incapacitated but ‘perfectly happy’ patients to be denied treatments that they had previously refused:

‘It seems unfair to stop treating you, because, you know, you’ve made a plan, earlier on and you’re actually perfectly happy.’ (IN-6).

A number of participants raised the possibility that difficulties might occur where healthcare professionals did not agree with decisions made by patients in ACPs, either feeling that the decision was not in the patient’s best interests from a clinical point of view, or if the professional had some ethical concern with the decision. This might be a particular problem if patients tried to make advance requests for specific treatments:

‘Also... it depends if the, what the advance sort of directive... well what the most appropriate thing to do clinically is... if there’s a conflict there... what would you do then?’ (ISWE-10).

‘Equally, it can make it difficult, I suppose, if ethically, you don’t always agree with the decisions they’ve made...’ (ISMH-19).

‘No, I think the only ethical problem would be if they tried to insist on a treatment that was not felt to be appropriate...’ (INEE-15).

One GP and one of the Psychiatrists demonstrated some uneasiness about a perceived relationship between ACP and assisted suicide, seeking assurance that ACP could not be used to request positive actions in end of life care:

‘Well you can’t make decisions to actually do anything positive, can you? Advance directives are only to avoid life ext... I think there are safeguards there.’ (ISMH-17).

One GP also suggested that perhaps there was a risk that in making an ACP one was giving control away, and that it was in this way ‘disempowering’:

‘There is a bit of a fear that it’s not empowering at all, that actually it’s very disempowering, and I’ve given the control away.’ (IN-2).

Quite a frequent concern among participants (with 16 references from 10 sources) was the possibility of coercion of patients when making ACPs. It was felt that great care would have to be taken to ensure that all was as it seemed, particularly when dealing

with relatives. Participants pointed out that it might sometimes be difficult to establish the true nature of patients' families and their intentions, particularly where financial matters were involved:

'Coercion, I suppose... you know, if someone is elderly and thought about it... you know, you hope their relatives have their best interests at heart, but they may not... And 'I think as a GP it's quite difficult to tease that out... if they come across as caring, supportive people, but they're fleecing them at home... you really don't know.' (IN-8). 'It's difficult, because as a doctor you have to act in the patient's best interests and unless you've got proof that they... you know you could have some kind of nefarious relatives wanting to get rid of their parents or people sooner rather than later, or rather than what the patient actually does want...' (INEE-12).

Finally, one of the Psychiatrists voiced personal concerns regarding what he saw as the inappropriate use of ACP by some patients to try to manipulate healthcare professionals. He had experienced a number of instances of patients with borderline personality disorders trying to make use of advance decisions to refuse treatment after having taken overdoses and felt strongly that this should not be allowed to occur:ⁱⁱ

'We've come across a few at the hospital, people with borderline personality disorders who make advance directives that they shouldn't be resuscitated if they take an overdose. And that always causes problems at, well it doesn't always, but it usually causes huge problems at A+E, and often the physicians interestingly, I don't know if this is your experience from this, sometimes feel 'yes, this person has capacity, let's just let them die.' Whereas, actually, I think that's wrong. I think that the people who drafted up these Bills, the Mental Capacity Act never envisaged borderline people using them to play with overdoses. That was never part of their thoughts, so it's being misused by this group of people, and in fact, at the time when they've taken an overdose they're actually distressed... you shouldn't let them die basically, in that situation. So I feel, you know, pretty clear about that.' (ISMH-16).

ⁱⁱ Further discussion established that this participant was referring in part to the case of Kerrie Woollorton, a young woman who having swallowed a quantity of antifreeze was admitted to hospital and subsequently died having refused treatment. The ACP document she carried with her in fact proved irrelevant as she was deemed conclusively to have capacity to refuse treatment. Interestingly this case was also referred to by a number of witnesses for the Commission on Assisted Dying to highlight their concerns about the difficulty of establishing mental capacity in patients who may be suffering from a mental disorder when considering requests relating to assisted suicide. The case was widely reported in the national media: BBC News. Doctors forced to allow suicide. 1 Oct 2009. Available from: <http://news.bbc.co.uk/1/hi/england/norfolk/8284728.stm>

8.1.3.12 *Ideas for improving ACP*

Aware of potential barriers to and problems with use of ACP, many participants were keen to offer their suggestions for improvement.

One of the most commonly mentioned, (with 16 references at 8 sources), was the issue of publicity and promotion of ACP, particularly with regard to public knowledge about ACP and willingness of the general public to engage with the process. Some felt that Government mailing of information on ACP to the public would be a useful approach, as well as promotion on television, radio and in written media. Two participants suggested that reference to ACP on EastEnders would be likely to result in significantly increased public awareness, with one commenting:

‘We live in a cult of celebrity, so I don’t know if Beyonce or, who else have we got... I don’t know, you know, some of the sort of pop groups, decided that they were all going to do advance directives... Something that um, appeals to the younger age group, to challenge, or to raise the issue of having advance directives.’ (INEE-15).

Two of the Psychiatrists interviewed felt that doctors, as ‘experts’ on ACP, had a responsibility for promotion and education regarding ACP, arguing that general practice was an ideal place for this and suggesting that practice leaflets or posters urging people to consider discussing ACP with the doctor or practice nurse might be useful; a number of participants felt that more printed information about ACP to give to patients would be an advantage.

Acknowledging the limits of their own knowledge on ACP, participants felt a need for more training in ACP and recommended that this should be started at an early stage, with teaching on ACP taking place at medical schools as well as on GP training programmes and at postgraduate meetings:

‘I think it should be something we teach in GP training... We do try and um, teach something about the Mental Capacity Act, and these things tend to go cyclically, so the trainees seem to select... obviously these things are in the RCGP syllabus as well.... I think these things should be taught at medical school.’ (ISWE-10).

Several also felt that shorter, more accessible guidance on ACP for professionals would be helpful, with one asking that this be ‘only one sheet of paper!’ (INEE-14), and others suggesting that there might be a place for a pro forma which would be recognizable and acceptable to other professionals.

‘I think you need a sort of pro forma that would be easily understandable, and looks like a legal document that anyone would accept.’ (ISWE-11).

With several participants commenting that ACP was not something that could be addressed at the end of an appointment or in a normal 10 minute GP consultation, one suggested that time for ACP discussion be clearly set aside and signposted to give the best opportunity to talk through the issues involved:

‘I think probably the thing to do would be perhaps to say, “well, it might be a good idea if we use this opportunity to talk about these sorts of things and can you make another appointment?”’ (ISMH-17).

Six participants pointed to a need for ACP to become a more normal and routine part of patient care, with regular review of existing ACPs also carried out:

‘It just needs to be just part of what we do with patients...’ (IN-1).

‘I think the only way is to review it, on a regular basis...’ (IN-8).

One GP suggested starting this process by looking at particular groups of patients, such as perhaps those who required frequent visits, to consider offering ACP to them.

A number of GPs also had thoughts regarding communication with other professionals, with ideas about delegation or sharing of the workload of ACP with professionals such as nurse practitioners or palliative care staff; one GP felt that perhaps a locally recognized professional such as a solicitor or other legal advisor with specific expertise to whom people could be referred for advice would be helpful:

‘The other thing is delegation of that, and that’s where using our nurse practitioner... for instance this morning I’ve done an unscheduled palliative care visit and left the district nurses doing that discussion... So it’s a matter of sharing it out among the team rather than just the GP doing it...’ (INEE-13).

Communication with colleagues was felt to be important, making sure that out of hours staff were kept informed about ACPs, as well as for the purpose of sharing ideas about use of ACP:

‘It is a matter of basically keeping the out of hours doctors up to date with what’s going on.’ (INEE-15).

‘I think knowing what other people do would be good.’ (INEE-14).

Finally, five participants stressed the importance of involving families in discussions about ACP. It was felt that families have a lot to offer in terms of information when discussions are taking place about ACP and that in addition ACP was much more likely to be useful where families were aware of its existence and had been involved in the discussions that resulted in it being made:

‘Have the family on board as well... I think the best discussions are where the family are aware of what could happen... and they are then able to help you to sort of take that discussions as to the way it happens...’ (IN-5).

‘I think it’s making sure that the relatives know... because they’re the people that are likely to be around.’ (IN-8).

8.1.4 Views of Old Age Psychiatrists

The four Psychiatrists interviewed tended to express broadly similar views to the participating GPs. Overall they were supportive of ACP as a concept and in favour of its use, particularly in primary care, with all four declaring this to be an appropriate environment for ACP, making positive comments about GPs suitability for the task of initiation of ACP:

‘GPs, or primary care physicians and staff, are in a good position in a way because they should have an understanding of all the aspects that are involved in a case.’ (ISMH-17).

They were also supportive of GPs in this process, with willingness to help with assessment of capacity for ACP where this proved to be complex.

With the exception of one, who had current experience of working in memory clinics, the Psychiatrists shared the GPs lack of familiarity with recent legal changes regarding ACP, with some similar confusion about terminology, and described relatively infrequent professional exposure to ACP:

‘Not a great deal, no. I’ve read about it.’ (ISMH-18).

‘I haven’t had any practical experience of having to deal with one, which is perhaps why I sound a bit sort of unsure...’ (ISMH-17).

Psychiatrists did however seem to express relatively more, and more detailed, concerns on ethical issues, with nearly a third of the total comments on this theme being made by Psychiatrists. Agreeing with GPs about the difficulties of predicting future wishes, one had specific concerns about the possibility of a connection between some patients’ desire to relieve burden on relatives and refusal of treatment, while another worried about the potential for misuse of ACP by patients themselves.

Finally, this group of participants seemed particularly keen to offer advice on improving ACP in primary care, with all four having a number of suggestions to make relating to publicity and promotion of ACP:

‘I don’t know how you do that, but raising the profile in some way, so that it’s not just seen as something you do when you get a diagnosis of cancer, or dementia... I think general practice is actually quite a good place to raise awareness because you’re seeing

a lot of people with chronic conditions... And you know, you can perhaps have information in the surgery for people to have a look at, you can have something in your practice leaflet about it, that, you know, 'if you want to make an appointment with the GP or practice nurse to discuss these things...' (ISMH-18).

8.1.5 Summary: semi-structured interviews

1. Participants were supportive of the concept of ACP with several expressing personal interest in making ACPs. Advantages of ACP included: facilitating decision making, avoiding conflict, relieving family burden, giving patients control, and saving costs.
2. While often unfamiliar with the term, most had a broad understanding of the concept of ACP as discussion and planning of future care in anticipation of loss of capacity. However participants had little exposure to ACP, and few regularly carried out ACP.
3. Participants lacked familiarity with guidance on ACP with none being aware of the RCP guideline. Knowledge and understanding of the legal status of ACP were generally superficial, with participants lacking knowledge of the elements of ACP provided for by statute and confused about changes in terminology.
4. Participants were aware of a variety of barriers to ACP including: discomfort with discussion, cultural reluctance to talk about end of life, conflict with clinical opinion, lack of time, and lack of knowledge about ACP.
5. Primary care was considered to be an ideal environment for ACP, with GPs well placed to introduce the subject. ACP was believed to be suitable in a variety of long term, chronic or life limiting health problems, or following life changing events.
6. A number of problems with ACP were identified, including: family disagreements, difficulties in following ACPs, lack of understanding, or availability when needed.
7. Ethical concerns about ACP included: difficulty in prediction of future wishes, professional disagreement with decisions, association of ACP with assisted suicide, potential for coercion and misuse of ACP, as well as inappropriate interpretation.
8. A number of factors were suggested to improve ACP in primary care: greater publicity, professional training, guidance and standard forms, making ACP routine, involving other professionals, improving communication, and involving families.

8.2 Focus group

8.2.1 Participant demographic data

Lay people were recruited for the focus group through the Norfolk Patient and Public Involvement in Research group (PPIRes). Six lay people participated, all of them women. Their ages ranged from 62 to 79 years (mean 69 years).ⁱⁱⁱ Most were retired, with one continuing to work in an administrative and advisory role for a local council education department. With previous experience including nursing, sociology and social research, and care home management, participants described a range of current interests relevant to the discussion of ACP including membership of a local Older Person's Forum committee, and interest in management of death and dying and specialist palliative care services.

The demographic data for focus group participants are available in Appendix 5 (see section A5.2).

8.2.2 Focus group process

The focus group discussion lasted for 92 minutes, ending after the planned 1½ hours when all items on the prompt sheet had been addressed and no further comments from the group were forthcoming. No problems occurred during the focus group, and there were no interruptions. Through their involvement with PPIRes, the participants had some understanding of research and experience of this kind of group discussion in the past and discussion seemed to flow well, with individuals respecting each other's contributions and giving opportunity to all to speak. Most of the discussion was led by BH, but AH (academic supervisor) was also present as a second facilitator, and added a few additional questions where further clarification of the ideas expressed by the participants seemed appropriate.

ⁱⁱⁱ Only 19% of registered General Practice patients in Norfolk fall within this approximate age range (65-84 years), with the 15% in the East of England and 14% in England. However, as noted previously, (see Chapter 7, section 7.4.2), in recruiting for the focus group the intention was to gain interested and informed views rather than necessarily a representative sample. These data (from the 2011 Census for England and Wales) were obtained from the Norfolk Insight website. Available from: <http://www.norfolkinsight.org.uk>

The recording was of good quality with speech clearly audible and different participants identifiable for the purposes of distinguishing between them. Transcription was therefore possible without difficulty.

8.2.3 Analysis of data

Following transcription of the recording, thematic content analysis of the data resulted in a number of key themes being identified. As the purpose of the focus group was to gain the view of lay people on the ideas and issues discussed in the interviews with GPs and Old Age Psychiatrists, and the discussion was prompted using a guide derived from the interview guide with description of what seemed to be some of the key reactions of interview participants (see Appendix 4, see section A4.12), themes necessarily closely followed those identified in the interview data, and consequently the same coding framework was used:

- General reaction to discussion
- Concept of ACP
- Experience of ACP
- Familiarity with legal status
- Support for ACP
- Advantages of ACP
- Barriers to ACP
- Carrying out ACP
- Problems with ACP
- Ethical issues
- Ideas for improvement

As lay people, participants were not expected to be familiar with professional guidance on ACP and this was not discussed.

However, analysis of the focus group discussion did reveal some different ideas expressed by the participants, often based on personal experiences of ACP with family members, with strong views expressed on the importance of ACP and how it should be carried out, as well as the sense of a belief in ACP as a right for patients.

The following pages describe the key themes in detail, illustrated with relevant quotations from the focus group transcript.

8.2.3.1 *General reaction to discussion of ACP*

Participants in the focus group had been provided in advance with some information on ACP in the form of a lay summary of the research project, as well as a list of some of the questions asked of GPs and Old Age Psychiatrists in the interviews (see Appendix, see section A4.10). The discussion began with the same question as the interviews: *'What do you understand by the term advance care planning or 'ACP'?* Having had

some information in advance, participants seemed perhaps more confident from the outset in terms of their responses, but there was still some hesitancy with regard to definition, with answers tending to be formed as questions:

‘FG-3: Is it... at first reading... is it similar to what’s called a living will? Where you write down...’ (Focus group).

Participants were clearly interested in the discussion and in each other’s views, giving full responses and often extending the discussion with other participants without the intervention of the facilitators. A number had significant personal experience in the area of ACP about which they were able to talk at length, with some strong views expressed with regard to these experiences. In addition, a surprising degree of comfort in discussing issues relating to ACP and end of life care was apparent within the group, with frequent laughter and use of humour, sometimes black humour, through the discussion, as this exchange, following on from a conversation about a patient with a ‘do not resuscitate tattoo’, illustrates:

‘FG-1: I can’t see GPs though... suggesting that we all go round with large tattoos!

General ‘No!’

FG-3: It could be a money earner for them though couldn’t it? They could have a tattooist in the surgery!’

Laughter.’ (Focus group).

There tended to be agreement with the views expressed by interview participants, and in fact some seemed to show a sense of support for GPs with regard to the difficulties of carrying out ACP, or even sympathy, as demonstrated when one participant was commenting on the timing of discussion of ACP:

‘FG-1: But I wouldn’t like to be in a GP’s shoes...’ (Focus group).

Overall there was a feeling of strong support for ACP, with firm agreement with the advantages of ACP suggested in the interviews, and use of positive language and supportive comments was evident in the same way as in the interviews. Participants clearly felt that ACP was an important process that should be openly discussed and promoted, and several of them had themselves already taken advantage of ACP. Consequently, they were especially keen to offer views on how it might be improved, particularly with regard to public knowledge and availability of information on ACP.

Participants were very strongly on the side of patients, and gave the impression, through various comments as well as the often forceful tone of voice used, that as a group they

were forming a view of ACP as a right and a necessity for patients, with strong views expressed regarding their expectation of provision of ACP by healthcare professionals:

‘FG-2: So the GP needs to do it beforehand then. Don’t wait until she’s in hospital and she’s got a week to live... it’s cruel...

Well they need to make the time for these appointments.’ (Focus group).

From this point of view they were highly critical of the healthcare system where they felt it failed patients, particularly relating to some of their personal experiences with family members, and any negative reaction to ACP expressed by the group tended to occur mostly in this context.

8.2.3.2 *Concept of ACP*

Despite having had some introduction to ACP in the information sent to them prior to the session, focus group participants tended to show a similar lack of familiarity with the term to clinicians, while at the same time having a reasonable grasp of what ACP might involve:

‘FG-1: Well the basis of this, is allowing somebody to make an informed decision, when they’re able, and then once they’ve made it, as [FG-5] said then that should be respected.’

‘FG-2: But as I understand, and there was a bit on a television programme last night, that you know people going into hospital... whether they want to be resuscitated or not, if Granny’s maybe going a bit senile... while she’s still capable, is she going to make plans for what she wants for the future.’ (Focus group).

One participant, who had some experience in talking with older people on an advice line was particularly clear on the need to establish capacity where making an LPA:

‘FG-1: You know, the question we get asked about, “My mother’s got, you know, the early stages of dementia, I need to do an LPA.” The key question we have to emphasize is, “Does she have mental capacity? Would your GP sign the form?”’ (Focus group)

Participants agreed with clinicians on the close association of ACP with end of life care, although they felt that this did not necessarily always have to be the case.

‘FG-5: I just see it as end of life care... Standard end of life care...

Several other participants: ‘yes’ or murmured agreement.’ (Focus group).

Pointing to the use of ACP to make decisions about where individuals wish to live or be cared for, one participant also highlighted some confusion about terminology where ACP seemed to describe a variety of different kinds of decisions or situations:

‘FG-1: I mean the only thing that I’m aware of is people who make a slightly different plan about whether they want to go into residential care or not. But that is bizarrely also called advance care planning, which might be confused.’ (Focus group).

8.2.3.3 *Experience of ACP*

Although an initial question about experience of ACP produced little response from the group, in a similar way to the clinicians, participants were more familiar with the use of powers of attorney and several had actually made them for themselves. As the following exchange demonstrates, mention of power of attorney also prompted further discussion around the subject of ACP and end of life care with five of the six participants subsequently relating personal experiences of the use of ACP:

BH: Has anyone come across any Lasting Powers of Attorney...

Lots of murmurs of agreement

Two: ‘I’ve got one’

FG-5: I’ve only done it verbally, so I was saying that...

Murmurs continue

BH: Sorry, how have you gone about doing that verbally?

FG-5: Well, in both cases I’ve been rung up by the medical profession to discuss end of life care, because it was obvious, it was six, one, two, six months in one case, in one case a few days, and in another case another six months... what did I want to do? And I said do not resuscitate, hospice straight from... because I had discussed it with my relatives.

BH: Yes, of course...

FG-5: So I knew their wishes...’ (Focus group).

This discussion also highlights the use of verbal ACP, with the participant being aware of her relatives’ wishes because she had discussed end of life issues with them prior to them becoming ill or being admitted to hospital, but with no decisions having been formally documented.

Another participant, who had with her husband made a formal advance decision to refuse treatment which they had lodged with their solicitor, had similar experience of the problems of not having formally discussed and documented ACP, and the difficulties that can sometimes then arise where relative’s interpretation of patients’ wishes conflict with clinical opinion:

‘FG-3: Well my husband and I have written something to say that we don’t want to be resuscitated and that’s with the solicitor, but that’s just one small part of advance care

planning, but the other one is that my stepmother-in-law, if you can figure that out, she had a massive stroke, and we went to hospital, and we saw the Consultant, Registrar first, who wanted to put a PEG in and I was with her, I'd been looking after, and her son-in-law, my husband was, and also [her] brother was there and we all said don't put the PEG in, let her go, and the Consultant overrode it.' (Focus group).

One participant also had some professional experience of ACP, having given advice to others about powers of attorney on a helpline for older people:

'FG-1: We are often asked about people who want to make powers of attorney, don't know that it's changed, so we have to explain that it's now in two parts, and we have an advisor who goes out and helps people do it and perhaps obviously to discuss the issues with the client. But I mean my husband and I, we did the old Enduring Power of Attorney, which is purely material and financial...' (Focus group).

8.2.3.4 *Familiarity with legal status*

There was some evidence of familiarity amongst members of the focus group with the legal status of ACPs, with an understanding that ACP allowed patients to make advance refusals of treatment which would be treated as binding, but not to request particular treatments:

'FG-3: Where you write down what you don't want to happen basically, rather than what you do want to happen?' (Focus group).

More familiar with the terminology about powers of attorney, at least one participant had a clear understanding of the term Lasting Power of Attorney and that these could now be made for both financial and health and welfare decisions in contrast to the previous Enduring Powers of Attorney which only covered financial matters:

'FG-1: Because they're now in two parts aren't they, unlike the old ones, pre 2008, and part of it is... I can't remember the exact title... is a financial assessment one which this is nothing about, but then the other part is about health and care...' (Focus group).

However, there was clearly some confusion however about the rights of relatives in terms of decision making where there was no power of attorney in existence, with one participant expressing surprise that having been asked to act as next of kin by a friend might not be enough to allow her to participate in decisions about her in the future:

'FG-5: Because a friend of mine who has got no family, has asked me if I would be her, I use the word next of kin, I know it's not legal, but I'm the person there to turn to, and I had said yes. But that could be overridden you're suggesting?' (Focus group).

8.2.3.5 *Support for ACP*

Participants were very much in favour of the use of ACP, believing like the clinicians that it was an important process the use of which should be encouraged.

‘FG-4: I’m all in favour of that. I think it should have been brought in ages ago. (Focus group).

‘FG-2: It’s not talked about, and it should be.’ (Focus group).

The level of this support was particularly demonstrated by participants’ interest in ACPs for themselves, with several already having made powers of attorney, and a number having made some form of verbal statement in the past or had relevant discussions with their family. One participant stated her likely intention to make an advance decision to refuse treatment relating to resuscitation if she needed to go into hospital:

‘FG-5: I haven’t been in hospital for ages, but I can see me now taking a little envelope saying, “This is my advance care plan: do not resuscitate if... You know, and please do not... for me it’s important because I’ve seen it... please don’t let me die alone. I don’t care if it’s a stranger, but somebody there.”’ (Focus group).

As mentioned above, participants seemed to see ACP as something patients should be entitled to; the following exchange, showing participants’ reaction to the mention of a member of the public who was reported as having a tattoo reading ‘do not resuscitate’, perhaps supports this view, with admiration shown for someone who ‘stuck up for her rights’:

‘FG-6: I think it’s brilliant!

FG-3: Well there’s no refuting it is there? They can’t say...

FG-6: Absolutely not... That’s strength of character isn’t it! Knowing what you want....

FG-3: Yes it’s great guts isn’t it?’ (Focus group).

8.2.3.6 *Advantages of ACP*

Focus group participants agreed with GPs and Psychiatrists on the potential advantages of ACP for clinicians, families and patients. One felt, in common with one of the GPs, that ACP might be particularly helpful in allowing those left behind to feel that they had carried out the persons’ wishes, while another pointed to the potential for ACP to allay some of the fears patients might have about the future:

‘FG-3: I think one of the advantages... of having an advance care plan, is that it does make people... the people left, feel much better that they’ve actually carried out their

loved one's wishes. That's very important after the bereavement, you know, it helps the grieving persons.' (Focus group).

'FG-6: I agree with all of that. It will give them more confidence. They must be frightened about the future, what's going to happen, if nobody tells them...' (Focus group).

Describing her positive hopes for ACP and its use, one participant referred to what she felt might be another significant benefit of ACP, reduction of healthcare costs through savings in unwanted or inappropriate treatments:

'FG-3: Well I would hope it's for... I think I hope it's for the benefit of the patient and family. I hope it's also good medicine. And then, out of that, always have to come cost savings, because presumably you're using, you'll be able to use fewer drugs, because you've got a plan, and people aren't madly trying to prolong life...' (Focus group).

8.2.3.7 *Barriers to ACP*

Participants were able to suggest a variety of factors that might act as barriers to ACP, mostly supporting the views of clinicians in the interviews. However there was sometimes some criticism implied; agreeing that clinicians might sometimes lack the necessary knowledge to initiate or discuss ACP with patients, one participant commented:

'FG-1: They may not have as much information actually. I mean I'm not so sanguine about... from being a medical rep, I'm, that disabused [sic] me forever about what GPs might or might not know, I have to say. It was fascinating.' (Focus group).

Participants were also surprised to hear that clinicians might be uncomfortable with discussing the subject of ACP and bringing it up with patients, and that they might be worried about upsetting people by discussing ACP:

'FG-5: And why are GPs so sensitive about it? They're dealing with sensitive subjects all the time!' (Focus group).

Furthermore, the following exchange demonstrates how, as one GP had wondered, the group felt that people might not mind their GP asking them about ACP and might actually be happy to discuss it:

'FG-6: Do you know, I don't think I would have a problem if my GP said that...

FG-2: I wouldn't mind no...

FG-3: I wouldn't...' (Focus group).

In contrast, participants suggested that another barrier might be the sensitivity of relatives to discussion of end of life issues, with several stating that close family members were unwilling to discuss these matters because they found it too upsetting:

‘FG-6: And that distressed my adult daughter. She didn’t want to think that I might be ill... No I can’t raise it with my daughter, so... She gets very distressed. But it’s a fact of life!’ (Focus group).

There was strong agreement with clinicians that the time required for ACP would be a major barrier, with some evidence of sympathy for GPs in terms of workload and a feeling that it would be extremely difficult for them to find the time to address ACP adequately:

‘FG-1: But can you imagine the GP having the time, in a busy practice.’ (Focus group).

Finally, participants agreed that there were likely to be inequalities in the availability of ACP to patients, with expense being a particular factor with powers of attorney. They seemed surprisingly accepting of the suggestion that ACP might be more easily offered by clinicians to a certain type of person, as the following exchange shows:

‘BH: Do you think there’s a problem of some patients getting the advantage of this and others not. GPs had a concern that this was going to be, mainly because of people knowing about it, that this was going to tend to be a middle class, intelligent, well educated, people who get on with their GP, type activity...

FG-5: It was ever thus!

FG-3: Yes exactly! So? Look at us!

General laughter...

FG-5: It’s going to be those who can argue, who aren’t afraid of authority... and I’m afraid it was ever thus.’ (Focus group).

However the importance of public knowledge and provision of information about ACP was highlighted, with the group well aware of the difficulties in establishing healthcare messages within communities:

‘FG-3: But surely we need to know that it’s possible to say this. I mean, we can only ask the questions if we know...’ (Focus group).

‘FG-1: Well, wherever, you know, and you could say to somebody, ‘what do you think about this’ and they would just look at you blankly. So it really is, it’s not just the message, it’s the penetration, it’s the targeting, and it’s the repeating, constantly repeating, because that’s the only way you get messages through. And it’s ten years to get some health messages through.’ (Focus group).

8.2.3.8 Carrying out ACP

There seemed to be agreement amongst participants that primary care was a particularly suitable environment for ACP to be carried out, with GPs appropriate professionals to offer it to patients:

‘FG-2: Well they are, they’re the whole centre of it.’ (Focus group).

However, as the following exchange shows, there was also some discussion about the possibility of other professionals offering ACP to patients, particularly nurse practitioners, with one participant seeming to suggest she might prefer to discuss ACP with a nurse rather than a doctor:

‘FG-5: Well lots of GP surgeries have nurse practitioners these days...

FG-1: Hmm, which is back to the idea of... I would prefer, in a way to discuss it with, if the GP is not, is too busy or whatever, I mean, I think a good nurse practitioner, has worked their way to the top and often knows...

FG-2: Well yes, and now they’re doing so much more...

FG-6: Maybe much more thorough than GPs...’ (Focus group).

Participants agreed with the suggestions of clinicians in terms of situations or conditions where the use of ACP might be appropriate, and were able to make a number of suggestions themselves, with specific mention of cancer and dementia as well as other conditions:

‘All rapidly offering suggestions at once:

FG-1: Parkinson’s.

FG-3: I would imagine strokes.

FG-2: Even severe diabetics newly home...

FG-3: What about even just with mini strokes?

FG-5: Oh no they can, I mean, my partner survived that...

FG-3: Oh I know it’s not a question of survival, but there’s a possibility that... I mean it’s a delicate one isn’t it? Because there’s a possibility that if you’ve had one you might have another, so is that the time when you might think about, ‘Well what happens if you have it?’ (Focus group).

With regard to the timing of ACP, participants acknowledged the potential difficulty in identifying ‘the right time’ to discuss the subject of ACP, but felt strongly that concern about this should not be allowed to delay the process. Discussion in the group established a clear belief that ACP should be carried out earlier rather than later, preferably when the person was relatively well and more able to consider important

options. However should a significant new diagnosis arise unexpectedly, professionals should act quickly to establish ACP decisions if they were not already in existence:

‘FG-2: I think this is where the GP has to start it. When a patient is in a relatively well state, to think about it, and having made their thoughts, come back and discuss, “Well if I go into hospital and this happens, I don’t want resuscitation or whatever...” But if they’ve gone to the hospital for maybe liver tests and they’ve found liver cancer, and that can be pretty quick and nasty, well then maybe, before they do anything, the GP or perhaps the solicitor should be saying something.’ (Focus group).

8.2.3.9 Problems with ACP

Focus group participants seemed well aware of the potential problems resulting from family involvement in ACP. It was recognized that disputes could sometimes arise where families did not agree with what patients had decided previously, and that patients’ families may sometimes be difficult for health professionals to deal with, particularly given the emotional viewpoint that they may inevitably have in these situations:

‘FG-2: And it seems very often the emotional side comes in when the family don’t want something, they start saying, “Well why didn’t...” and this is something I’ve seen in the community, and can be terrible... “Granny’s had a op, well why did they do that? They should have let her die in peace.”’ (Focus group).

Participants very much agreed with clinicians regarding the problems relating to communication of ACP decisions and the difficulties of ensuring that these are made available to the right people in the right place at the right time, as the following comments demonstrate:

‘FG-2: Well this is what they want to do... but what they were saying is that whatever you’ve got, it’s communication, and they can’t access notes here there and everywhere all the time. And maybe it’s the next morning before you can get the GP on the phone, and this sort of thing. Too late then...

FG-3: By which time the ambulance has come, and done what they have to do...

FG-2: Yes. Hmm. I wouldn’t want that.’ (Focus group).

Relating to this, a number had specific concerns, based in personal experience, regarding communication with families and others close to patients. Several had experiences where views of families, sometimes based on patients’ previous verbal wishes, seemed not to be taken into account where they conflicted with clinical opinion and the group was highly critical of these instances of what they saw as poor care:

‘FG-3: She had a massive stroke, and we went to hospital, and we saw the Consultant, Registrar first, who wanted to put a PEG in and I was with her, I’d been looking after, and her son-in-law, my husband was, and also Madeline’s brother was there and we all said don’t put the PEG in, let her go, and the Consultant overrode it.

FG-2: That’s bad.

FG-3: Absolutely bad.’ (Focus group).

In addition, there was a strong feeling that healthcare professionals might be over cautious with regard to issues of confidentiality when it comes to discussing patients with their relatives or carers, leading to further important information about their wishes being lost or ignored:

‘FG-1: And one of the things that does come up occasionally is that family... wanting, out of genuine concern, wanting to discuss with a GP care, sometimes future care of an older relative, and the GP being very resistant to doing this and citing law, saying that there’s patient confidentiality and they’re not allowed to do it.’ (Focus group).

8.2.3.10 *Ethical issues*

Similar ethical concerns were discussed in the focus group as in the interviews, with a discussion taking place about a possible relationship between use of ACP and rationing. Participants were well aware of the need for cost savings in the NHS and some worried that there might be a temptation to take advantage of ACPs to save money on expensive treatments:

FG-5: I always have some concerns, there’s been something in the press over the last five years, where healthcare is restricted by age. And it was in the press again this year. I would be concerned that if you had an advance care plan, that somebody would look at it and say, ‘Hmm well we won’t bother to treat her cancer, or his... because they’ve got an advance care plan, we’ll just...’ (Focus group).

Participants showed agreement with clinicians concerns regarding the potential for coercion within families in terms of ACP decisions:

‘FG-3: To get back to your question, I think family should understand what’s going on, and perhaps be consulted. But I think that families are difficult beasts aren’t they? And so there could be all sorts of reasons for a daughter’s or husband’s or...’ (Focus group).

‘FG-4: Yes, I agree. You could get someone wanting to inherit the money, yes. You could get people persuaded perhaps... Or just told...’ (Focus group).

The problem of how it would be known if a patient changed his mind after making an ACP was also acknowledged:

‘FG-3: Yes, yes. But the question is, how do we know? Well, what happens? How do we know, how does anybody know if you’ve changed your mind? Compos mentis I mean...’ (Focus group).

Finally, there were a considerable number of comments relating to care and withdrawal of treatment at the end of life, with many expressing preferences regarding themselves and relatives for comfort care at the end of life and avoidance of treatments and interventions perceived as unnecessary, with an impression given that participants hoped ACP might help them achieve fulfilment of these wishes:

‘FG-6: My mother had a massive stroke, and she died in hospital, she had a stroke on the Monday, and it took her ‘till the Saturday to die, and it was horrendous and there was no possibility of her coming back. Now I’d have given anything to have pulled that switch... you know, I really would, and so would my family.’ (Focus group).

In fact there seemed to be a feeling that current medical practice was still failing to address palliative care appropriately, and that medical developments as well as ethical and legal concerns might have contributed to this, with a perception that doctors might now be afraid to give sufficient medications to patients at the end of life:

‘FG-2: Well I’m all for giving the best possible comfort care that you can. But, some people are afraid, and I think that the old fashioned idea, of the GP just easing his patients path... Good GPs are worth their weight in gold. But now I think, maybe I’m wrong in saying this. That a lot of GPs are almost, with all the things that have happened, afraid of overstepping the mark...

FG-6: It would be easier for doctors if they, if the law removed the fear of prosecution for what they see as assisted suicide...

FG-4: Just think, a few years ago, you wouldn’t have this conversation, would you, because you couldn’t resuscitate people like they do today, so they just died. And that was the end of it.

FG-2: A peaceful, comfortable way of sliding off...

FG-4: Just got too clever...’ (Focus group).

8.2.3.11 *Ideas for improving ACP*

Having discussed the various barriers to and potential problems with use of ACP, members of the focus group had a number of ideas for improvement of ACP. There was a clear belief that ACP should be offered routinely, and that while GPs might be appropriate people to introduce this, perhaps it was mentioning it to patients that was most important rather than who did it:

‘FG-2: I was hoping that, when this is done, that when people go in to see the GP, at some point, that as part of an annual health check, the GP will discuss this with the patients... The point is that shouldn’t it be discussed with everyone by the GPs, if anybody’s ill, bad kidneys or whatever, age factor doesn’t come into it, but certainly in the over 65s...’ (Focus group).

‘FG-1: Yes. But I don’t think it matters whether it’s the nurse or the doctor, I think it just needs to be somebody...’ (Focus group).

Agreeing with interview participants, there was a strong feeling that there exists a real need for more public information on ACP, with a number of comments about the potential value of mention of ACP in television or radio soap operas such as *EastEnders* or *The Archers* as a means of improving public familiarity with the concept and suggestion that promotional material should be available in suitable public places.

‘FG-5: I think you could get... a piece of literature, almost as you have explained in your outline to us, and you get that to libraries, you get that into chemists, you get it into GP surgeries...’ (Focus group).

In fact there was a view that this might be much more important than focusing on training for health professionals:

‘FG-3: Everybody says, “training, we all need more training”, you know, “doctors need training how to talk about death and dying, blah, blah, blah, blah.” I mean, there has to be other ways doesn’t there, to get the message out as well? And which comes first, the training? There’s no point doing the training if it’s just going to be falling on deaf ears...’ (Focus group).

Finally, participants agreed that family, notwithstanding the potential conflicts and difficulties inherent in dealing with families, had a valuable contribution to make to ACP and should be involved in discussions:

‘FG-6: I think it’s terribly important also to put your feelings to your immediate family. Because, to the obverse side of the coin, they’ve got to deal with your death...’ (Focus group).

8.2.4 Summary: focus group

1. The focus group showed a similarly positive view of ACP in primary care to that of GPs and Psychiatrists, with a belief that GPs are well placed to carry out ACP. There was a high degree of personal interest in ACP with several having their own.
2. With one participant having had professional experience of ACP, the focus group showed similar degree of understanding of the concept to the clinicians and shared a level of confusion about legal status.
3. Participants agreed with professionals on the likely advantages of ACP, with some very similar sentiments expressed regarding the usefulness of ACP for bereaved families. It was agreed that ACP was suitable in the various medical conditions mentioned by clinicians.
4. There was general support for GPs, including support in terms of recognized time constraints, and understanding of barriers faced by both patients and professionals in ACP. However there was also some criticism of GPs knowledge, and surprise at their discomfort in discussing ACP, with expression of their own comfort in this.
5. The group recognized problems highlighted by clinicians such as family disputes and communication of decisions, but also had specific concerns about the weight given to families views, believing that professionals focus too much on patient confidentiality.
6. Similar ethical concerns were described in terms of patients changing their minds, coercion and rationing. Strong views were also expressed about comfort care and ACPs ability to achieve this, with criticism of the medical profession regarding provision of pain relief at the end of life.
7. Relatively accepting of inequalities compared with clinicians, focus group participants were still keen to suggest ideas for improvement of ACP, largely aligned with the ideas of clinicians. They stressed the importance of involving families and were particularly keen to make ACP a routine part of care, and to increase publicity, focusing on public information rather than professional training.

8.3 Questionnaire survey

8.3.1 Participant demographic data

Questionnaire participants were drawn from 142 general practices in the counties of Norfolk (118) and Essex (24) (Norfolk and North East Essex PCTs). Over the course of the survey, a total of 730 questionnaires were sent out, of which 258 were sent to practices in Essex, and 472 to practices in Norfolk.

Significant difficulties were encountered in recruitment to the questionnaire survey, and there was a very poor response from Essex practices with only 20 questionnaires returned, amounting to an 8% response rate in this area. Following this, the recruitment strategy was altered, with smaller packs of questionnaires sent out to a larger number of practices in Norfolk. As a result, a further 106 completed questionnaires were returned (22%). Overall, 126 (17%) questionnaires were completed and returned, of which 89 were from clinicians and 37 from practice managers.

As planned, demographics data were not sought from practice managers, but clinicians were asked to give their age, sex, and the number of years they had been in their current role. Of the clinicians, 34 (39%) respondents were male, and 54 (61%) female (one respondent did not state a sex). The youngest respondent was 31 and the oldest 61, with the largest proportion of respondents coming from the 51-60 years age range (46%).ⁱ

Most of the clinicians who completed questionnaires were qualified GPs (82%), with 14 (16%) practice nurses, 1 (1%) GP Registrar, and 1 Community Matron. Ranging from less than 1 year to 34 years, many respondents had been in their current position for a considerable time, with 38% having been in this role for more than 21 years.

The complete demographic data for questionnaire participants are displayed in Appendix 5 (see section 5.3).

ⁱ These data suggest a slightly older group than might be considered representative, with 35% of GPs falling within the closest regional (Norfolk, Suffolk and Essex) age band (50-59) according to 2012 data (the comparable national figure was 30%).

As with the interviews, there was a greater representation of females amongst our sample than either the regional (Norfolk, Suffolk and Essex) percentage of female GPs (42%) or the national figure (47%).

These data were obtained from the Health and Social Care Information Centre website, available from: <http://www.hscic.gov.uk>

8.3.2 Survey process, and analysis of data

Apart from the difficulties in recruitment, no other significant problems were encountered in carrying out the survey. Returned questionnaires were completed clearly, and participants generally answered all questions, though relatively few completed any of the spaces allowed for free text comment. A small number of participants left one or more of the demographics questions blank.

Following data extraction into Microsoft Excel, numerical data were analyzed using SPSS, while free text comments were imported into NVivo for qualitative analysis. In describing these results, the format of the questionnaires will be followed to a large extent, addressing the various questionnaire sections and questions in turn.

8.3.3 Questionnaire for clinical staff

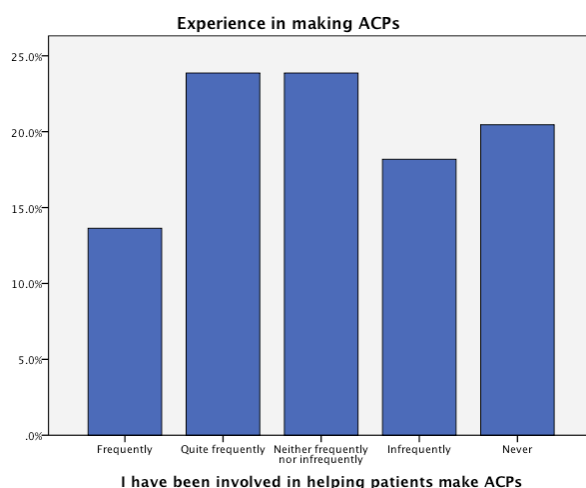
Results are described over the following pages with respect to each question or section of the questionnaire. The proportion of respondents answering in a particular way is quoted as a percentage, along with the total number of respondents answering the relevant question. In this description the word ‘agree’ will refer to where participants selected ‘1’ or ‘2’ on the rating scale (1 = strongly agree to 5 = strongly disagree). The full dataset, with frequencies of responses as well as median scores for each question is available in Appendix 6 (see sections A6.1.1-A6.1.10).

8.3.3.1 Question 1: ‘What is your experience of ACP?’

Most clinicians (68%, n=88) described themselves as familiar with the concept of ACP as described in the information given on the front of the questionnaire.

However, while 14% felt that they encountered patients with ACPs frequently, six participants (7%, n=88) had never encountered such a patient, and eighteen (21%, n=88) had never been involved in helping a patient make an ACP (Chart 1).

Chart 1



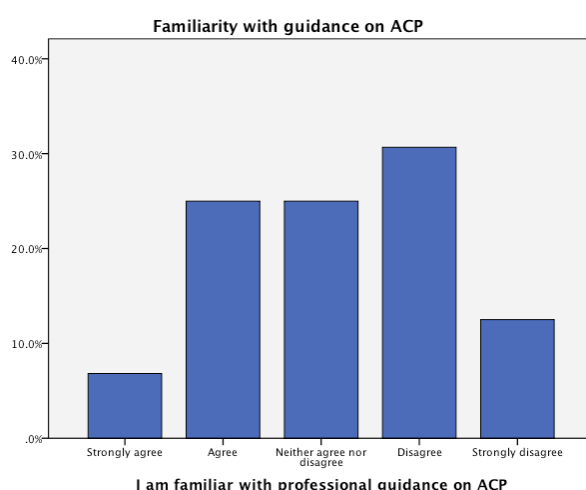
8.3.3.2 Question 2: ‘What are your feelings about helping patients make ACPs?’

Clinicians were strongly supportive of ACP, with seventy seven participants (89%, n=87) agreeing that they were in favour of the concept, and 70% (n= 89) agreeing that it is important to offer patients ACP in primary care and that GPs have an important role in this. Slightly less, but still the majority (63%, n=89), agreed that they would want to

be involved in this process themselves. Participants also generally agreed that more ACP should be carried out in primary care (63%, n=89).

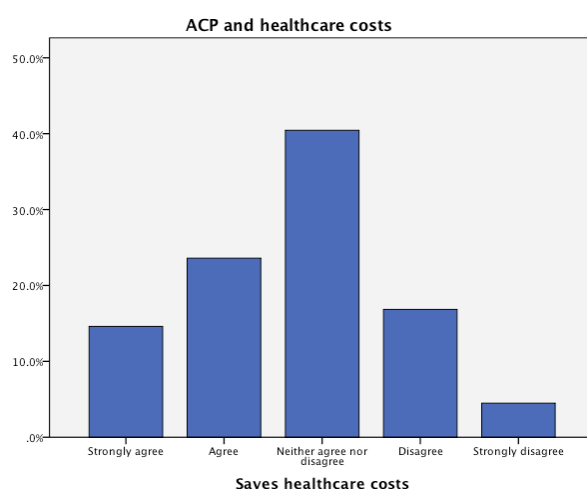
Numbers were much smaller when considering confidence in knowledge about and use of ACP, however, with median scores for these questions falling at the centre of the five-point scale (3). Only 41% (n=89) agreed that they were confident in helping patients make ACPs, with marginally more (48%, n=89) confident in assessing mental capacity for ACP. No more than six clinicians (7%, n=88) were able to agree strongly with the statement *'I am familiar with professional guidance on ACP'* (Chart 2), with only four (5%, n=88) expressing similar confidence in their understanding of legislation governing the use of ACP.

Chart 2



8.3.3.3 Question 3: *'What do you feel are the important benefits of ACP?'*

Responses demonstrated high levels of agreement amongst clinicians with positive statements regarding the benefits of ACP, with the majority agreeing that ACP helps communication (87%, n=89), reduces stress and anxiety in patients (73%, n=89) as well as relatives and carers (74%, n=89), gives patients control over their future care (88%, n=89), and makes decision making easier for clinicians (79%, n=89), and for relatives and carers (81%, n=89). Participants also agreed that ACP was likely to reduce inappropriate investigations and treatments, as well as hospital admissions. However, respondents were less convinced of the ability of ACP to save healthcare costs, with only 38% (n=89) agreeing with this statement and most clustered around the middle of the scale (median score = 3) (Chart 3).

Chart 3

Four participants took up the opportunity to add comments on the benefits of ACP. Two identified additional benefits: giving patients choice and a voice in their care, and building a relationship between patient and clinician. One highlighted the need for review of ACPs, while another pointed out that ACP, *'should reduce unnecessary tests / admissions, but doesn't always work like that!'*

8.3.3.4 Question 4: *'In what specific medical conditions or situations do you feel ACP might be useful?'*

Participants were offered the option of selecting up to six conditions or situations in which they felt ACP might be useful. The majority ticked every option, with the highest numbers choosing 'terminal illness' (99%) and 'dementia' (96%) and the smallest number selecting 'frailty' (76%).

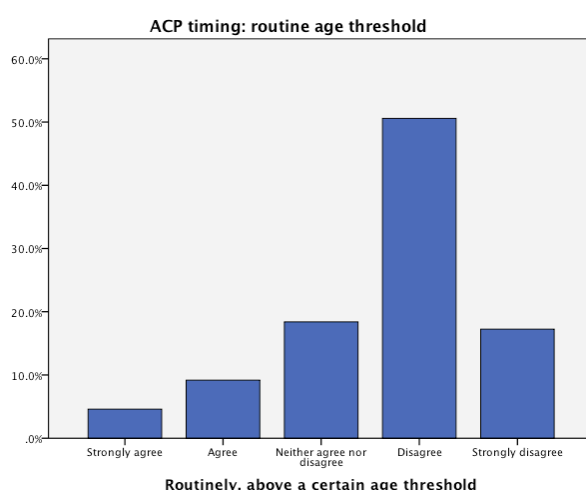
Thirty seven participants (42%) chose to add other comments, which described a wide variety of conditions or situations relevant to the use of ACP. Amongst these comments there were forty five mentions of neurological conditions, with four qualified as 'progressive' or 'degenerative'. Respiratory conditions occurred seventeen times, with four comments mentioning 'severe', 'end stage' or 'advanced'. Of twenty four other relevant comments, in addition to a few other medical conditions, there were four mentions of 'everyone' and seven of 'any chronic or life limiting condition', with one participant suggesting, *'Any medical condition which affects speech or ability otherwise to communicate effectively.'*

A fuller breakdown of these comments is available in table form in Appendix 6 (see section A6.1.4).

8.3.3.5 Question 5: 'What do you feel is generally the best time to carry out ACP with patients in primary care?'

Clinicians were lukewarm in their agreement (41%, n=88) that ACP should be carried out '*as early as possible*' with most responses clustered around the centre of the scale (median score = 3). There was more agreement with the suggestion that ACP should be carried out at around the time of a new diagnosis (57%, n=87), at a time of relative wellness (68%, n=87), and routinely in certain medical conditions (63%, n=87). However, very few considered the idea of ACP carried out routinely above a certain age threshold an attractive one (Chart 4), with only four (5%, n=87) strongly agreeing with this suggestion and most tending towards disagreement (median score = 4).

Chart 4



Eighteen participants gave additional comments with regard to timing of ACP, with eight of these comments relating clearly to a view that timing depends on the patient either in terms of when ACP may be felt by the clinician to be indicated, '*as clinically appropriate*', or when an individual prompts the clinician in some way, '*when patient asks*.'

Various mentions were made of 'change' or 'deterioration' in a patient's condition as the stage at which the clinician might consider carrying out ACP, with several comments on the need for regular review of ACP or review at any change in condition.

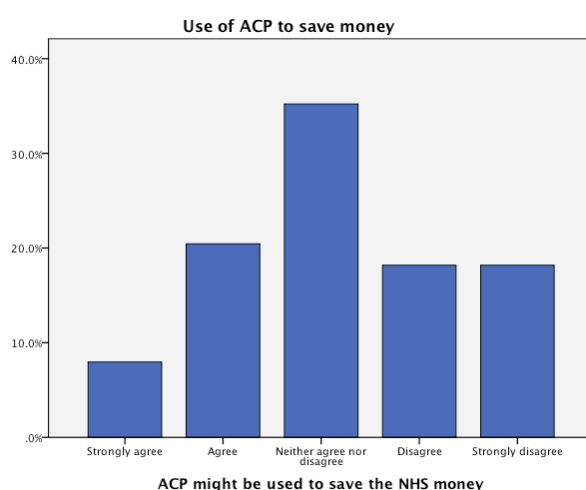
8.3.3.6 Question 6: 'What do you feel are the important practical and ethical problems with ACP?'

Although few felt strongly about these statements, clinicians showed a moderate degree of agreement with suggestions that ACPs may be difficult to interpret (58%, n=88),

difficult to apply in practice (61%, n=87), may conflict with clinical opinion (64%, n=88), and may not be available when needed (69%, n=87). There was very strong agreement (95%, n=88) that if ACP is left too late patients may lack capacity to participate, but many participants were also aware of difficulty in identifying the right time to carry out ACP (67%, n=87).

From the point of view of patients, there was support for the view that it is difficult to predict future wishes for the purposes of ACP (60%, n=87), and for the concern that patients may change their minds after making ACPs (61%, n=88). Coercion in decision making seemed a lesser, though still significant, concern, with 42% (n=88) of participants choosing the centre value on the scale and only 8% strongly agreeing that coercion was a problem. The possibility of ACP being used to save the NHS money (Chart 5) similarly seemed to be less of a concern for most, with 18% (n=88) strongly disagreeing with this, although with agreement of 29% this was still relevant for some.

Chart 5



A number of other problems were raised by participants in additional comments. Several mentioned concerns about time constraints, and difficulties with interpretation and professionals' lack of knowledge. One was also concerned about potential dispute amongst patients and family members and the difficulty of predicting future wishes: *'Patient and relatives may disagree. Despite forward planning, they often change their minds when faced with death.'*

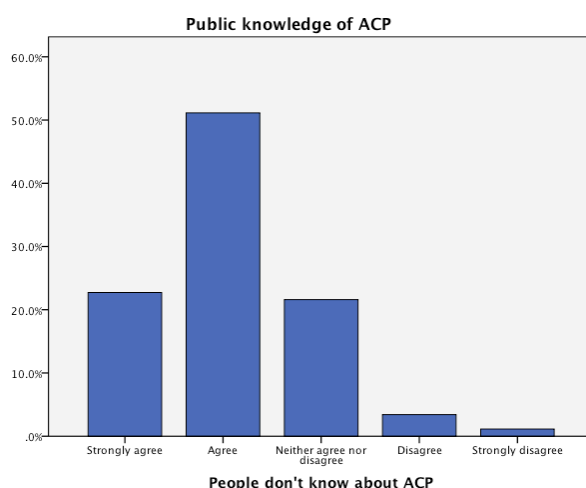
8.3.3.7 Question 7: *'What do you feel are the important barriers to making ACPs?'*

Clinicians agreed that availability of ACP is a significant barrier for some patients (62%, n=87) as well as physician discomfort with discussion of ACP (63%, n=88).

Quite strong agreement existed for the statement *'people don't know about ACP'* (74%, n=88) (Chart 6).

Respondents seemed a little less sure that ACP taking up too much time was an important issue (52% agreement, n=88), however, and only one (1%, n=86) strongly agreed that ACP is 'too expensive' (median score = 4).

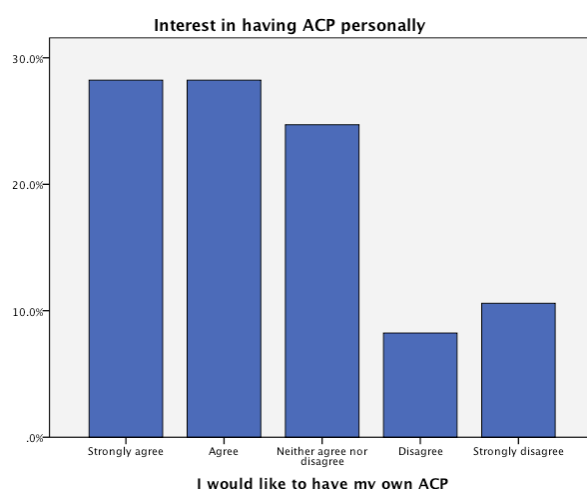
Chart 6



Several participants made further comments on this question, with two considering 'lack of standardization' in the process of ACP as well as available documentation to be an important barrier to its use. One mentioned culture and religion, while 'capacity issues' were also noted as a concern.

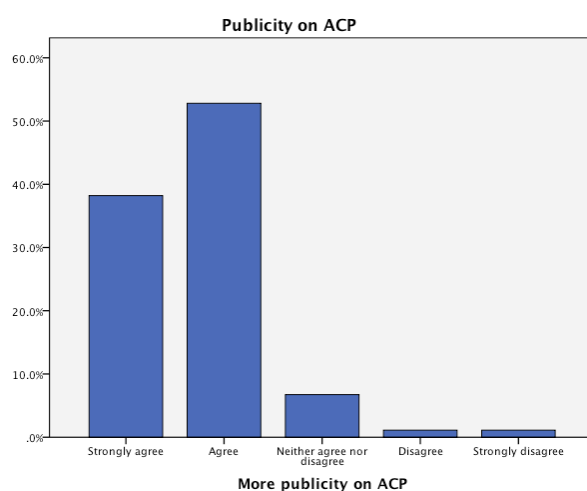
8.3.3.8 Question 8: *'Would you like to have an ACP for yourself?'*

More than half of respondents agreed that they would like to have their own ACP (56%, n=85), although the spread of responses might suggest a degree of uncertainty (Chart 7). 53% (n=85) also agreed that they would advise close family members to make ACPs. However, very few felt it likely that they would make their own ACP in the next year, with only one participant (1%, n=85) strongly agreeing with this statement; one did have an ACP already, and another added a handwritten comment, *'No, but I have already made family aware of wishes.'*

Chart 7

8.3.3.9 Question 9: 'How do you think we might best improve use of ACP in primary care?'

In terms of ideas for improving ACP in primary care, responses demonstrated strong support from clinicians for the suggestion of involving other healthcare professionals in providing ACP (82%, n=89), as well as for more training for clinicians in ACP (89%, n=89). One of the highest levels of agreement with any statement was reserved for the suggestion (Chart 8) that there should be more publicity on ACP (91%, n=89), while many also agreed that ACP should be made a routine part of care (63%, n=89), and that a brief pro forma for ACP would be useful (74%, n=88).

Chart 8

Clinicians also made a number of other comments about improvement of ACP: one raised concern that a pro forma might be *'too prescriptive and not allow patients to*

make their own decisions’, while another reaffirmed the importance of standardization and transferability of ACP. One felt that making ACP routine would be particularly helpful: *‘If ACP becomes routine, it will break down barriers to implementation and discussion.’*

8.3.3.10 Question 10: *‘Do you have any other comments or thoughts on ACP in primary care which you would like to draw to our attention?’*

This final question allowed for free text comments from participants on any relevant issues, with twenty one participants recording additional views. These comments were found to fit within the existing thematic coding frame used for the interviews and focus group, with most participants choosing to mention issues relating to perceived barriers to ACP and ideas for improving use of ACP in primary care. A few comments related to individuals’ experience of ACP, however, with one respondent having designed an ACP document for use in his practice, while another explained how discussions about preferences regularly took place without necessarily being labelled as ACP or formally documented.ⁱⁱ

‘We gave a practice DNAR and advance directive document which I designed.’

‘I always discuss end of life care preferences in terminal illness but not formalised in a document (except DNR).’

A number of potential barriers to ACP were mentioned, most of which related to the problem of finding time to do this in busy general practice:

‘10 minute consultations are not appropriate to assess this type of problem, as often these patients also have co-morbidities that also need addressing.’

‘Although in principle it is a good and worthy idea, I am concerned it may only increase and stretch our stress and resources!’

One participant also commented on the discomfort felt by clinicians in discussing ACP with patients, while another was concerned at reluctance of other professionals to be involved in the process:

‘Difficult and awkward subject to discuss.’

‘Clinicians other than GP e.g. community matrons and end of life nurses are very reluctant to sign these documents even if they have discussed the issues. They would

ⁱⁱ Here participants made use of common abbreviations (DNAR and DNR) for the phrase ‘do not attempt resuscitation’.

prefer the GP to take responsibility even if they know the patient less well than the nurse. It seems to be an issue over legal liability.'

Various ideas or comments relating to improvement of ACP were offered, with several addressing a need for standardization as well as regular review:

'It needs to be seen as a dynamic evolving document that can be changed as required.'

'How do they remain active documents, yet accessible to all HC professionals?'

'It would help if the process was standardized and subsidized.'

One clinician mentioned the need for further publicity on ACP:

'Need to demystify this in the public domain – education is key.'

Finally, a few participants referred to ethical problems with the use of ACP, including the problem of accessibility in terms of cost, as well as the concern that patients might change their minds when faced with the reality of a future medical condition. One also raised a concern about the use of 'do not resuscitate' orders, suggesting that these might be promoted in a bid to reduce pressure on services:

'In my experience, Power of Attorney is the most useful and least accessible ACP because of the cost of using a solicitor.'

'Problem with it being routine is that preference may change significantly when the patient finds themselves in situation where it might come into play (i.e. theory different to reality).'

'Too often DNR notices are requested by care homes without discussion with patients. The ambulance service are advocating them to reduce their workload.'

8.3.4 Effect of respondent characteristics on clinician questionnaire responses

With demographic data collected for clinicians including age, sex, professional role and number of years in that role, it was considered important to establish whether any of these factors might influence the way in which participants responded to the questionnaire.

Data analysis was carried out in SPSS, with non parametric tests used; Mann Whitney was chosen for comparing sex with the responses to other items in the questionnaire, while Kruskal Wallis was used for comparisons involving three or more groups, such as age range. The low numbers of non GPs, with fourteen Practice Nurses, one GP Registrar, and one Community Matron, did not support statistical analysis of the effect of professional role on responses. However, Mann-Whitney tests were carried out comparing the sex variable with response to all numerical items on the questionnaire, while Kruskal-Wallis tests were similarly performed to compare age of participants and the number of years they had been in their professional role with all items.ⁱⁱⁱ

Overall, participant characteristics appeared to have a minimal impact on the way they answered questions, with no effect for example of age or sex of participant or number of years in professional role on items such as familiarity with the concept of ACP, experience of ACP in terms of having encountered patients with ACP or helped patients make ACPs, confidence in helping patients make ACPs or in understanding of legislation and familiarity with professional guidance, although female participants did express less confidence in assessment of capacity of patients for ACP ($p < 0.005$). Similarly, participant characteristics largely seemed to affect neither views on the benefits of ACP nor the potential problems or ethical concerns with ACP, although the number of years the participant had been in his or her professional role did seem to affect views on whether ACP might be difficult to apply in practice with those with 11-20 years experience being least likely to agree that this was the case ($p < 0.05$).

Clinicians' sex, age and experience seemed to have no impact on personal support for ACP in terms of wishing to have one's own ACP or likelihood to recommend it to close family members. All three factors however appeared to affect participants' likelihood to consider there to be a need for more training for clinicians on ACP, with female

ⁱⁱⁱ Tables with the results of the statistically significant comparisons between participant characteristics and questionnaire responses are included with the rest of the questionnaire data in Appendix 6 (see section A6.2).

participants, those who were younger, and those who had been in their current role for less time being more likely to support the suggestion of more training ($p < 0.05$). The youngest group of participants were also more likely to believe that ACP should be carried out at a time of relative wellness ($p = 0.005$), and females tended to feel more of a need for greater publicity on ACP ($p = <0.005$).

8.3.5 Internal consistency of questionnaire

A number of the questions or statements within the questionnaire for clinicians were thought to address similar ‘themes’ in terms of knowledge, views or experience of clinicians in ACP.^{iv} Consequently it seemed relevant to consider the consistency of responses to these items using an appropriate measure of internal consistency. Cronbach’s alpha coefficients were therefore calculated using SPSS for the following unified ‘themes’ believed to be represented by groups of questionnaire items: ‘experience of ACP’ ($\alpha = .863$), ‘confidence / knowledge about ACP’ ($\alpha = .862$), ‘supportive of ACP in primary care’ ($\alpha = .917$) and ‘positive about benefits of ACP’ ($\alpha = .901$). These figures suggest satisfactory internal consistency in participants’ responses to similarly themed questions.

^{iv} Further details of the items included within these themes are displayed in a table in Appendix 6 (see section A6.3).

8.3.6 Summary: questionnaire for clinicians

1. Participants claimed quite high levels of familiarity with the concept of ACP, but admitted to infrequent experience or involvement in ACP in common with interview participants. However there was strong support for the concept, with most agreeing with positive statements drawn from interview comments about benefits of ACP, and more than half of participants wishing to have their own ACP.
2. Relatively low agreement with statements about familiarity with guidance as well as understanding of legislation supported findings of interviews, with participants lacking confidence in use of ACP with patients.
3. There was near universal agreement that ACP was appropriate in terminal illness as well as dementia; participants also suggested various neurological conditions. However, less agreed that ACP be carried out early, routinely or at a time of wellness, and very few agreed with the focus groups' suggestion to use an age threshold for routine ACP.
4. Participants showed moderate agreement with most of the practical and ethical problems with ACP identified in interviews, though less seemed concerned about the possibility of coercion and few agreed that ACP might be used to save money. Public knowledge was considered to be an important barrier to ACP, but few were concerned about cost. Time taken to carry out ACP was not generally felt to be a significant barrier although a few did raise concerns about this.
5. In common with interview participants, there was very strong support for increased publicity on ACP as well as professional training and involvement of other professionals. Many agreed that a brief pro forma for ACP would be useful.
6. Participants' characteristics in terms of sex, age and time in current role seemed to have minimal impact on responses to the questionnaire, although there did seem to be an effect on a few items, with participants who were female, younger, and had less experience in their current role being more likely to support further training for clinicians on ACP.

8.3.7 Questionnaire for Practice Managers

Results are described over the following pages with respect to each question or section of the questionnaire. Rating scores were not used in this questionnaire, with Practice Managers instead being given the options ‘yes’, ‘no’ or ‘don’t know’. The proportion of respondents answering in a particular way is quoted as a percentage, along with the total number of respondents answering the relevant question. Several of the questions on the Practice Managers questionnaire required a numerical response, for example the number of patients registered at the practice; these are commented on individually as many participants chose to qualify these numerical responses with written comments. A number of questions specifically asked for free text comments; again these are described individually. The full numerical dataset, with frequencies of responses where appropriate is available in Appendix 6 (see sections A6.4.1-A6.4.8).

8.3.7.1 Question 1: *‘How many patients do you have registered at your practice?’*

All but one Practice Manager supplied a figure for the total number of patients registered at their practice, with numbers ranging from 1900 in the smallest practice, to 16700 patients in the largest (mean 8450) and a good spread of different practice population sizes.

8.3.7.2 Question 2: *‘Are you familiar with the concept of ACP (as we have described it)?’*

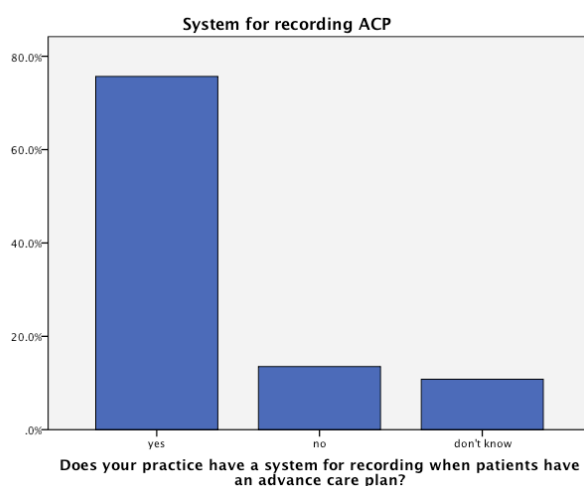
Almost all Practice Managers declared themselves familiar with the concept of ACP as described in the questionnaire (95%, n=37), with only two stating that they were unfamiliar with ACP.

8.3.7.3 Question 3: *‘Does your practice have a system for recording when patients have an advance care plan?’*

The majority of practices had a system for recording when patients have an ACP (76%, n=37) (Chart 9), with ten Practice Managers specifying Read codes as their method of recording this on the practice computer database. A few also mentioned placing an ‘alert’ on patients’ home screens, a system which would mean that the fact that a patient had an ACP would be visible to any clinician opening their record. However, several also mentioned that recording of ACP on patients’ notes was not necessarily done in a

systematic way: *'I would not be surprised if the recording is haphazard and inaccurate.'*

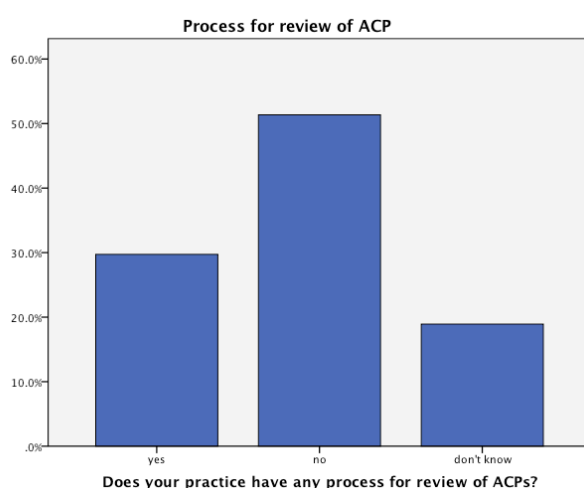
Chart 9



8.3.7.4 Question 4: *'Does your practice have any process for review of ACPs?'*

Practices seemed less likely to have a process for review of ACPs (Chart 10), with over half of Practice Managers replying in the negative to this question (51%, n=37).

Chart 10



In terms of time scale for any review, responses were varied, with frequencies ranging from monthly to annually, and one suggesting that review would be carried out at the patient's request and another *'at the time of end of life'*.

Seven of the Practice Managers mentioned palliative care or Gold Standards Framework meetings as the process whereby ACP might be discussed or reviewed, but a lack of

clarity was evident with some practices where ACP had quite recently started to be used:

‘As their use is relatively new for us and it is a patient held document we are not sure how this is going to evolve.’

‘Once the ACP is offered / given to the patient, it is unclear what input is expected, unless the patient asks for help.’

8.3.7.5 Question 5: *‘Please could you estimate the number of patients with ACPs in your practice? If possible, please run a computer search. (Suggested Read codes are at the end of questionnaire.’*

Nineteen of the Practice Managers provided a figure for the number of patients with ACPs in their practice, ranging from no patients to 149 (mean = 28, n=19). Nine of these figures were qualified in some way with additional comments. The practice with the largest number (149) had written ‘59 PPC 90 DNARS’ so it is unclear whether these were all individual patients; it is probable that a large number of patients had both a preferred place of care recorded and a do not resuscitate order, which would dramatically reduce the total. Several other comments were similarly unclear such as ‘37 with not for resus 12 PPC’ and ‘51 (41 DNAR)’. One further Practice Manager noted ‘209 on cancer register’ but with no indication that these patients had ACPs.

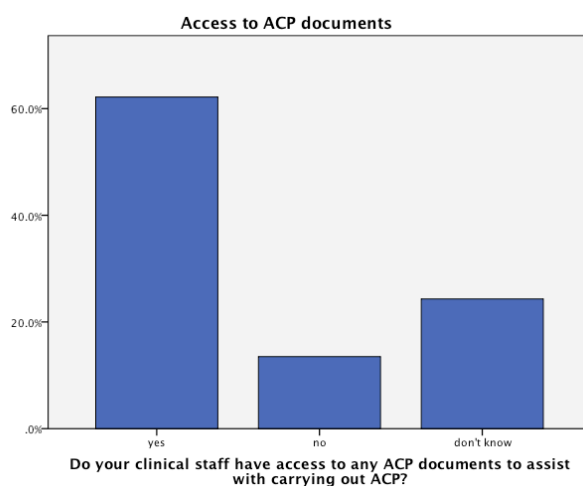
Despite these difficulties in interpretation, it is clear that as would be expected larger practices generally had larger numbers of ACPs recorded. In addition, those with the largest numbers tended, where they made free text comments elsewhere in the questionnaire, to refer to regular ‘palliative care’, ‘multidisciplinary’ or ‘Gold Standards Frameworks’ meetings. This suggests that, as is made clear from descriptions with the numbers provided by some practices, that the largest numbers of ACPs were generally made up of records of ‘preferred place of care’ and ‘not for resuscitation’ rather than any more detailed ACP documentation.

A table displaying more detailed information on the responses to this question, with practice list size and additional relevant comments is available in Appendix 6 (see section A6.4.5).

8.3.7.6 Question 6: 'Do your clinical staff have access to any ACP documents to assist with carrying out ACP?'

Most Practice Managers felt that their staff had access to some form of documentation to help with carrying out ACP (62%, n=37) (Chart 11).

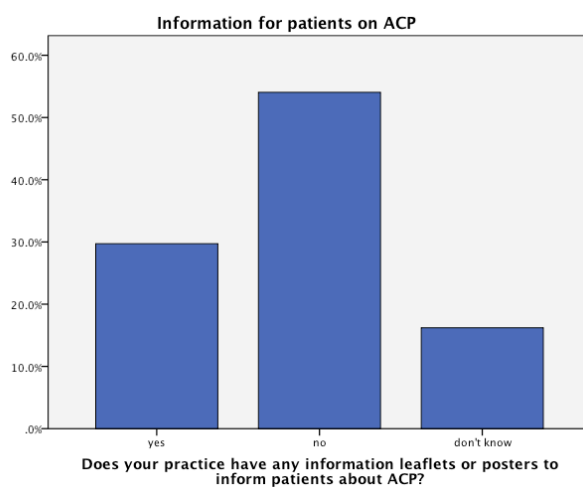
Chart 11



8.3.7.7 Question 7: 'Does your practice have any information leaflets or posters to inform patients about ACP?'

In contrast, far fewer of the Practice Managers were aware of having available any information leaflets or posters to inform patients about ACP (Chart 12), with 54% (n=37) answering 'no' to this question.

Chart 12



8.3.7.8 Question 8: *'Do you have any other comments or thoughts on ACP in primary care which you would like to draw to our attention?'*

In the same way as on the questionnaire for clinicians, this final question allowed for free text comments from participants on any relevant issues, with fourteen participants recording additional views. These comments were found to fit within the existing thematic coding frame used for the interviews and focus group, with most participants, in common with their clinical colleagues choosing to mention ideas for improving use of ACP in primary care. One Practice Manager, for example, mentioned having had 5000 copies of an ACP document printed for distribution amongst the practice patients, stressing the importance of making patients and clinicians consider ACP part of normal practice:

'I think we need to encourage use of them, having got 5000 printed. If we can include it in the green folder for all End of Life patients and consider it "normal practice" to issue, it would reduce the stigma/fright it may cause to patients who perhaps don't know their prognosis.'

Another referred very positively to a pilot scheme to introduce ACP, in the form of identification of people's preferred place of care and resuscitation preferences, into nursing homes, carried out by nurses (this practice also recorded the highest number of ACPs):

'Our residential nursing homes pilot nurses have been doing a brilliant job introducing PPCs and DNRs to nursing homes. They are now using ACPs. The practice staff have been slower to adopt them but are now using DNARs more routinely. More widespread use of such forms would ensure greater dignity and choice for patients in end of life situations and are to be encouraged.'

However, few seemed to have so much experience: it was suggested that 'local training' on ACP would be useful as well as *'guidance on standard procedure'*, with one Practice Manager commenting *'I don't know anything about ACP!'*.

Several participants mentioned potential barriers and problems with ACP, with one concerned not only about the amount of GPs' time it would take if done by them, but also the fact that the practice might not be kept up to date if other professionals outside the surgery were involved:

'Possibly time consuming, certainly for GPs, but if done by other clinicians external to the surgery (other than those involved in GSF meetings) practice will not necessarily be told / advised so cannot update records accordingly.'

One Practice Manager seemed to have a rather negative view on the process, complaining, *'This seems to be another complication added to clinical practice.'* However, others were more positive, with one writing, *'Needs sorting out! Good luck with your project!'*

8.3.8 Summary: questionnaire for Practice Managers

1. Almost all practice managers stated that they were familiar with the concept of ACP although subsequent responses and comments arguably suggest lack of clarity about this.
2. Most practices had a system for recording ACP, likely to be Read coding, although recording did not seem to be done systematically in most cases. Some practices also used a system of 'alerts' to highlight the presence of ACPs.
3. Few practices had any process for review of ACP. Where there was such a process it tended to be associated with palliative care or 'Gold Standards Framework' meetings rather than review with individual patients.
4. Very variable numbers of ACPs were recorded, with likely different interpretation of the concept. However, there tended to be more recorded at larger practices and those involved in palliative care or 'Gold Standards Framework' programmes.
5. Most Practice Managers believed that their clinical staff had access to documentation to help with ACP, but fewer had any information available for patients.
6. A few strongly positive views were expressed regarding programmes to increase use of ACP in individual practices. Other comments made by Practice Managers called for professional training and guidance, while several raised concerns about the time required to carry out ACP.

CHAPTER 9

Discussion

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9.1 Key findings

1. Positive views on ACP existed amongst primary care professionals with strong support for its more frequent use. Agreeing on ACP's likely benefits, professionals views showed close alignment with lay people, focusing on the importance of ACP in improving communication between patients, families and clinicians, as well as in decision making, and giving patients greater control.
2. There was evidence of some broad understanding of the concept of ACP. However clinicians' specific knowledge, particularly in terms of legislative provisions and professional guidance on ACP was significantly lacking. Furthermore, experience in use of ACP was infrequent, with a general lack of systematic recording and review.
3. ACP was considered useful in a variety of situations, with focus on its suitability for chronic and life limiting conditions including end of life care. With ACP felt to be particularly relevant in dementia, participants were aware of the risk of loss of capacity preventing patients' participation in ACP.
4. A variety of barriers to use of ACP were acknowledged, including discomfort in discussion, lack of knowledge, and time availability, with low public awareness also considered important. Particular difficulties were highlighted in ensuring that ACP decisions were effectively communicated with out of hours and emergency services.
5. Participants worried about the difficulty of predicting future wishes and the possibility of patients changing their minds after making ACPs, as well as the potential for professional disagreement with ACPs' content. They were also concerned about the existence of inequalities in provision of ACP, with recognition of cultural differences as well as financial and educational barriers.
6. A variety of suggestions for improvement of ACP in primary care were offered, including increased publicity, training for professionals, standardization of ACP including the availability of recognized forms, and involvement of other professionals and families in the process.

9.2 Introduction

A small, largely qualitative, study of primary care professionals, with additional input from old age Psychiatrists and lay people, this study provides a detailed picture of views, understanding and use of advance care planning in primary care in the East of England.

Primary care professionals in this sample showed some broad conceptual understanding of ACP, but limited detailed knowledge of the legal provisions for its use, minimal familiarity with relevant professional guidance, and infrequent exposure to ACP in practice.

However, participants did show a high degree of support for the use of ACP in primary care, as well as a keen awareness of the complexity of barriers involved in implementing ACP in this environment, and of the potential problems and ethical concerns with its use. Considering these issues, they were able to provide a variety of suggestions for improvement in the promotion and use of ACP in primary care.

Over the following pages, these findings will be discussed in more detail, examining them in the context of previous studies as well as making suggestions as to the direction of future research.

9.3 Attitudes to ACP

Literature suggests strongly positive attitudes of professionals,(23) patients(27) and families(29) towards ACP (see section 3.3), and the findings of this study demonstrate the existence of largely similar attitudes in the UK primary care environment. Both professionals and lay people were generally positive about ACP as a concept, appearing to be interested in the process and supportive of its use. Evidence from this study suggests the degree of support amongst primary care professionals to be particularly strong, with almost 90% of those surveyed in favour of the concept; this is in line with a previous study of physicians(25) but considerably greater than the support shown by General Practitioners (GPs) in one previous study.(26) The strength of this support was also demonstrated by the commitment of professionals to make more use of ACP and to offer it more frequently to their patients, with the majority keen to be involved in the process, time and resources allowing.

A shared view existed that ACP was something that everyone might usefully consider, in a similar way to a testamentary will, and, from the point of view of the lay people involved in the study as well as some professional participants, that ACP might even be

a right to which all should be entitled. Many participants indicated the level of their support for the concept by a personal interest in having ACP, with more than half of the clinicians in the survey considering having one and advising close family members to participate in ACP also. In common with findings in the literature however,(88) (see section 3.6) there was already a tendency to procrastinate, with very few already having an ACP or considering it likely that they would make an ACP in the next year.

ACP did not seem to be a subject that people found difficult to talk about in concept, with participants happy to discuss and share their views. Lay people demonstrated a high degree of comfort in discussion, confirming the findings of other research (see section 3.3.5)(36,41) in their willingness to discuss ACP with their doctors, although, again confirming the literature (see section 3.6), they did complain about the reluctance of their relatives to engage in these discussions. Doctors on the other hand, happy to talk about ACP in an abstract and even personal sense, acknowledged their discomfort in discussing ACP with patients, confirming erroneous beliefs established in the literature(39,40) (see section 3.3.4) regarding a perceived potential for discussion of ACP to upset or depress patients, although some did show awareness that patients were actually often happy to be asked about ACP.

Various studies have established evidence of the beliefs of patients and healthcare professionals regarding perceived benefits and advantages of ACP, with key amongst these for professionals being recognition of patients' autonomy,(31) while improving communication and facilitating decision making(35,37) (see section 3.3.2). For patients, developing a sense of control over future care,(32) relieving burdens,(36) and strengthening relationships(32) were believed to be the most important outcomes (see section 3.3.5). Empirical studies have also provided evidence of beneficial outcomes of ACP in terms of reduction in anxiety among patients and relatives(61) (see section 3.5.3).

Participants in this study described similar benefits, with particularly strong agreement on ACP as a method of improving communication between professionals, patients and families. Perhaps showing the strength of understanding of some primary care professionals of their patients' views, clinicians and lay people expressed often very closely aligned views on the advantages of ACP for patients in terms of establishing feelings of control, allaying fears of the future and of being subjected to unwanted treatments, as well as for families in terms of lightening the burden of decision making and helping deal with bereavement. Decision making was clearly seen as an important

benefit for professionals and families, with a belief that ACP can, when done well, provide a clear guide for them to follow while avoiding conflict.

There is some evidence in the literature of a potential for ACP to result in savings in healthcare costs(54,64) (see section 3.5.4), and a number of participants expressed a view that this might be the case, with several GPs mentioning this in interviews and comments also made in the focus group. Although when mentioned in the focus group participants seemed largely comfortable with the idea, GPs interviewed tended to express significant discomfort from an ethical standing, with concerns about the implication that money might be a driver for ACP. However, in the survey, this was shown to be much less of a concern, perhaps due to the fact that participants seemed to have significant doubts about the effectiveness of ACP as a cost reduction measure.

9.4 Knowledge, legislation and guidance

Given the level of existing policy support for ACP in the UK, as evidenced by the existence of various programmes and documents promoting ACP (see section 5.2), it was perhaps surprising to find such a lack of familiarity amongst interviewed clinicians, both GPs and Old Age Psychiatrists, with the term ‘advance care planning’.

On subsequent discussion in interviews, most clinicians provided further description of their understanding of what ACP might involve (see section 8.1.3.2) which sometimes proved close to definitions provided in professional guidance.(172) This perhaps explains why clinicians in the subsequent survey, who had the opportunity to read a brief explanation of the concept on the front sheet of the questionnaire, having recognized the concept described, were more able to declare themselves familiar with this, although agreement in this group still only reached levels of familiarity shown in older studies of ACP(44,45) (see section 3.4). Practice managers, perhaps being more exposed to local initiatives regarding end of life care, and being given only a binary response option to this question, were even more likely to agree, claiming near universal familiarity with the concept, although answers to subsequent questions suggested the possibility of a degree of conceptual confusion about ACP amongst this group.

However, while some general understanding of the concept may have existed amongst participants, specific understanding of ACP was a different matter. Key to current implementation of ACP in the UK has been the development of legislation clarifying its legal standing and providing for effective and binding means of establishing wishes for future care. Consequently knowledge and understanding of the legislative framework

supporting ACP would seem to be crucial for those likely to be involved in helping patients to participate in the process. However this proved not to be the case, with GPs as well as Old Age Psychiatrists, lacking significantly in the clarity of their knowledge of this area. The MCA 2005 had been in place for five years at the time of the interviews, and there was some degree of awareness that it made provision for ACP, but this was far from universal, with considerable confusion shared by some professionals and lay people regarding the changes in terminology resulting from the MCA 2005, particularly with regard to powers of attorney, and very low confidence of clinicians in their knowledge about ACP legislation confirmed in the survey.

While the level of confusion about ACP demonstrated amongst primary care clinicians in previous studies prior to the implementation of the MCA 2005 might have been expected,(45) (see section 3.4) it does seem surprising now. However, these findings do support those of a recent study,(33) where Community Nurses using ACP tools such as the Gold Standards Framework still lacked confidence in their understanding of ACP especially in terms of the components of ACP provided for by legislation (section 3.4).

Nevertheless, discussion did reveal practical knowledge of the binding nature of advance decisions to refuse treatment, even if participants were unfamiliar with the term, with awareness that the law requires such decisions be respected. It was also widely acknowledged that ACP decisions could only be made if the person concerned had the required mental capacity, and that this would be assessed using the MCA 2005 test. Although less than half of clinicians surveyed felt confident in assessing capacity for the purpose of ACP, most of those interviewed seemed to have a fairly clear understanding of this test, with strategies to help in forming their assessment and appropriate referrals being made to Old Age Psychiatrists for further advice when the assessment was particularly difficult, a practice of which the Psychiatrists interviewed expressed their approval.

In this study we were interested to establish the awareness of clinicians of professional guidance on ACP, particularly that produced by the RCP.(172) Very few clinicians in our survey showed any evidence of detailed knowledge of professional guidance in this area, with very low awareness evident amongst those whom we interviewed; while vague mention was made of a number of the documents we had reviewed, (see section 5.3) no mention was made of the RCP document, and no participant described any of these in detail or claimed to use them in practice. Most openly admitted little knowledge of professional guidance on ACP, citing the huge volume of guidelines and paperwork

generally with which GPs are now expected to keep up to date as a reason for this. There was some suggestion that face to face teaching was more useful than guidance, with the most enthusiastic supporter of ACP describing such a session as having sparked his interest; there is some evidence in the literature of GPs placing a higher value in terms of change in practice on face to face teaching in the form of postgraduate clinical meetings than do hospital consultants, with both groups being less influenced by guidelines.(197)

9.5 ACP in practice

Literature(85,86) (see section 3.5.6) and guidance(172) (see section 5.3) suggest that primary care provides many conditions likely to facilitate successful ACP, and as such may be an ideal environment for its use. Participants in our study agreed with this sentiment, believing that the ability of primary care to provide continuity of care makes it a particularly suitable setting for ACP.

However, despite this, they lacked experience of ACP in practice, showing levels of experience similar to those demonstrated in pre MCA 2005 studies,(34) (see section 3.4) with some having never encountered a patient with an ACP, and those who suggested ACP to their patients being very few: one fifth of those surveyed had never had opportunity to help a patient to make one. Most GPs recounted experience that was sporadic at best, with occasional exposure to ACP in the form of documents, often already completed by patients, brought to the surgery to be recorded in the notes, being asked to participate in establishing capacity for powers of attorney, or rarely, suggesting ACP themselves in palliative or end of life situations. Surprisingly, Old Age Psychiatrists, who given their exposure to elderly patients and those with dementia in particular might be expected to have more experience, also cited only occasional exposure to ACPs.

Where clinicians did have more experience of ACP, it tended to be in the form of powers of attorney, although this was often only in the context of financial planning. A few practices had also clearly been involved in national and local schemes to establish preferred place of care and resuscitation decisions for patients considered to be at the end of life, with some GPs having experience of ACP in this context; this was supported by comments from Practice Managers on their questionnaires regarding 'palliative care meetings' and 'Gold Standards Framework', associated with often quite large numbers of patients quoted as having ACPs, generally in the form of documented preferred place

of care and cardiopulmonary resuscitation preferences. However, given the variability in responses and evidence of confusion about the concept of ACP, whether the examples given by Practice Managers always constituted ACP carried out with patients in any degree of detail is open to question.

GPs in our study were aware of a range of ways in which ACPs could be made, from verbal expression of wishes to families or health professionals, to formal written documents. Interestingly, lay people in the focus group recounted several personal examples of the use of verbal ACP with family members, perhaps relating to a view supported in the literature that patients may not necessarily feel a need to record ACP, being satisfied with discussion with family rather than proceeding to formal documentation of wishes(32,36) (see section 3.6). However, evidence(55) and logic would suggest that the availability of clear, documented decisions is likely to be key to ensuring that wishes about future care are followed, and GPs interviewed were well aware of this issue. Professional guidance on ACP (from the BMA, GMC, RCP and NEOFCP) has consequently recommended documentation and appropriate storage of ACP decisions as well as regular review to keep decisions up to date (see section 5.3).

Most of the professionals interviewed described an appropriate method of recording patients' wishes in their computer notes, and this was supported by Practice Managers, most of whom agreed that they had such a system. However this was not generally done in a systematic way, with various methods being used and awareness that existing methods failed in terms of making ACPs available at times of urgent or emergency care. The MCA 2005 Code of Practice (see section 2.6) as well as professional guidance (from the BMA, GMC, RCP and NEOFCP, see section 5.3) recommends regular review of ACP as a way to ensure that decisions remain valid. However, most practices had no systematic way of reviewing ACPs, with this generally left to patients, though where ACP was done as part of palliative care planning it generally resulted in some form of regular review, albeit not obviously with the input of patients.

The professional guidance reviewed (see section 5.3) suggests a number of situations and conditions in which ACP may be appropriate or useful, and studies have investigated its use in a variety of situations (see section 3.5.5). In our study, clinicians suggested a number of similar situations, with long term, chronic or life limiting health problems, or life changing events being considered important. Specific conditions most supported in the survey were terminal illness and dementia, with strong support for the use of ACP also in cancer, heart failure, and stroke, as well as frequent mention of

progressive or chronic neurological and respiratory conditions. Lay people were in agreement with these indications for ACP, with specific mention of cancer, dementia, Parkinson's disease and stroke.

Both interviews and focus group indicated a strong association of ACP with palliative and end of life care, supporting the connection with terminal illness. In addition, participants showed awareness of the relevance of ACP to capacity loss and thus to dementia as a condition with a high probability of loss of capacity. In fact dementia was considered particularly important in terms of timing of ACP, with a strong awareness of the risk of 'missing the boat' in terms of patients' capacity if discussions were left too late, an issue also recognized in the literature(78) (see section 3.5.5).

There was agreement with recommendations in RCP guidance, supported by the literature,(29) (see section 3.7) that ACP discussions should take place earlier rather than later, when the person is relatively well. However, both clinicians and lay participants also highlighted the appropriate use of ACP where a new or significant diagnosis is made (as recommended in NEoLCP guidance, see section 5.3). Lay people made the suggestion that ACP should be carried out routinely at a certain age threshold, interestingly an idea that has been suggested by patients in other studies(41) (see section 3.7) but one which found very limited support with clinicians in our study.

9.6 Barriers and concerns

A number of studies have highlighted a variety of barriers to ACP, with important factors evident from the point of view of both professionals and patients(88) (see section 3.6). In terms of physician barriers, discomfort in discussion of ACP has been considered to be of significance,(33,92) (see sections 3.3.4 and 3.6) and this was no different in our study, with over half of clinicians in our survey agreeing that this presented an important barrier to ACP: a belief existed among clinicians, confirming the findings of literature,(33) that early discussion of what were perceived as end of life issues was not considered acceptable in current practice. While lay people were rather perplexed by this, failing to see why doctors would be uncomfortable about this issue in particular, a few GPs offered perceptive comment on why this discomfort might exist. There is an understanding in existing literature(24,37) (see section 3.3.4) that clinicians may feel 'better qualified' to take the decisions involved in ACP, and concerned about patients making them without understanding. GPs in our study were similarly concerned, and suggested that a psychological difficulty might exist for some, used to

taking the lead in decision making, in relinquishing control to patients by offering ACP. This is perhaps supported by the near two thirds agreement in the survey with the suggestion that conflict with clinical opinion might be a potential problem with ACP. It is also possible that the concerns of some regarding a possible association of ACP with euthanasia might, in the context of continued public debate in this area, contribute further to discomfort in discussing ACP.

The limitations of time in UK primary care are well recognized,(198,199) with most appointments limited to ten minutes or less. While there has been suggestion in the literature that, with a stepwise approach, some elements of ACP can be addressed in a brief appointment,(200,201) lack of time is acknowledged as a significant barrier to ACP(93,94) (see section 3.6) and a number of clinicians in our study confirmed that ACP was not something they considered possible to address effectively in a ten minute appointment, at least not alongside dealing with other medical issues. Interestingly, lay people seemed to support them in this, expressing some sympathy for doctors in the difficulties they were likely to encounter in trying to find the time to address ACP. However clinicians' commitment to make use of ACP seemed strong, with only half of those surveyed agreeing that the time ACP takes would be likely to prove a significant barrier to its use; Practice Managers were perhaps more concerned about the limitations of their GPs' time than the GPs themselves, with several comments made in their responses about the amount of time that ACP might take.

Availability and recognition of ACP documentation was seen as a key issue with high agreement in the survey that a significant problem with ACPs was their not being in the right place at the right time. With less discussion noted in previous studies, this perhaps highlights another problem of particular relevance to UK primary care. While previous studies were largely carried out in residential nursing homes or secondary care, where ACPs once completed would generally be more available, in primary care, an ACP in the patient's notes might well be missed or inaccessible in an emergency or out of hours situation or if the patient were transferred to hospital.

Both GPs and Psychiatrists showed some degree of apprehension regarding the legal 'ins and outs' of ACP relating to their own lack of knowledge, linked for some to a concern that they might not be best placed to ensure that patients developed an ACP that was effective. Indeed, a genuine concern for patients' welfare was at the basis of some of the most pressing objections to ACP, not only in terms of their fear of upsetting patients, but also regarding the possibility that ACPs would be made without full

understanding of the consequences or that it might be interpreted too broadly, resulting in treatments being withdrawn inappropriately, both highlighted as a concern of physicians in previous research(34,37) (see section 3.3.4). More worrying was the suggestion by one Psychiatrist that lack of understanding of ACP by other healthcare staff existed to a degree that they believed an advance decision to refuse treatment in the form of cardiopulmonary resuscitation meant that that patient should receive no treatment at all.

It is possible that professionals' apprehension about legal issues may sometimes inhibit their use of ACP, and certainly lay people in our study felt that difficulties result from these kinds of feelings amongst clinicians, with a belief that overcautious behaviour on the part of professionals with regard to patient confidentiality hindered families' ability to assist with decision making. However professionals may be right to be cautious, considering the potential susceptibility of ACP to problems relating to coercion,(34) (see sections 2.6 and 4.6) and two fifths of clinicians surveyed in our study agreed that this presented an important problem with ACP. Acknowledged in the literature to be a difficult judgment to make,(34,119) (see section 4.6) some interview participants described the particular difficulties primary care professionals face in establishing the true nature of the intention of families in these situations. Although participants did not mention this, it is likely that changes in the requirements for powers of attorney under the MCA 2005 will bring GPs into more frequent contact with these problems in the future. Appointment of an LPA for health and welfare requires the completion of a certificate of understanding which includes a statement about absence of coercion; as GPs are named on the statutory form as a group of suitable professionals to complete these certificates they would seem very likely to be asked by patients and to have increasing involvement in this area.

In the literature a number of commentators discuss the difficulty of prediction of future wishes and issues of patients potentially changing their minds after making ACP,(106-108) (see section 4.3) with philosophical questions of 'personhood' forming part of a discussion about whether former selves should be able to bind future selves to decisions affecting healthcare.(2,119) However, it was perhaps surprising, given the fact that these were not clearly highlighted as major issues in previous empirical studies, to see the prevalence of these being identified as practical ethical problems by practising clinicians. Three fifths of the primary care clinicians surveyed felt that patients changing their mind and the difficulty of predicting future wishes presented important

problems with ACP, and a number of participants in the interviews suggested and discussed these issues readily, with several comments relating to ideas about current and future ‘selves’ and the specific problem of the ‘pleasantly demented’ patient with an ACP refusing treatment discussed in literature(108) (see section 4.3) being brought up by one GP. Perhaps the close relationship often developed between primary care professionals and their patients results in a particular resonance of these issues; certainly one interviewed GP described a belief that she knew a number of her patients well enough to be able to predict their wishes (see section 8.1.3.9).

Arguably well versed in the issue of health inequalities with regard to other aspects of care, clinicians were well aware of the possibility that ACP might be more available to certain groups of patients than others,(145) with nearly two thirds agreement in our survey that ACP might not be available to all patients equally, and a view prevailing that it might be an activity largely accessible to middle class, well educated patients, particularly those with whom the doctor felt more comfortable communicating. Acknowledging the impact of cultural differences on ACP that has been well established in the literature(27,136) (see sections 4.5 and 4.6), participants were also aware of the likely impact of cost of ACP on the ability of many of their patients to participate. One of the Psychiatrists interviewed highlighted the issue of literacy, referred to in the literature,(97) which she felt was of particular importance in her elderly patient population, many of whom she was aware lacked basic literacy skills.

9.7 Improving ACP in primary care

9.7.1 *Publicity and training: ‘I don’t think people generally know much about it.’*

Previous studies have demonstrated low awareness of ACP amongst healthcare professionals(44,45) (see section 3.4) but particularly amongst the general public,(27,28) findings that were confirmed in the beliefs of participants in our study. A number of previous investigations aiming to increase the use of ACP have focused on individual teaching interventions for ACP, with mixed success.(88) Participants in our study on the other hand were strongly in favour of much more general publicity on ACP, with very high support in our survey for this suggestion and frequent references made by both clinicians and lay people to the use of media including television and radio, and in particular the television soap opera *EastEnders*, as being likely to result in

significantly more public interest in ACP.ⁱ Our study therefore clearly indicated support for a much broader, community wide approach to promotion of ACP, one which has been demonstrated to be effective in what is arguably one of the most successful studies of ACP,(55) (see section 3.5.2) where a community wide education and promotional approach was taken.

Primary care was acknowledged by participants to be an ideal environment to help to promote this kind of community awareness programme, with posters and leaflets in GP surgeries, encouraging patients to ask their doctor or Practice Nurse about ACP; however, at present only half of practices had access to any promotional or informative literature on ACP for patients. Clinicians accepted their role in this, with a suggestion that healthcare professionals should be the experts on ACP, with responsibility to educate patients on benefits and use of ACP. Clearly in order to do this, their own knowledge would need to be of an adequate level. Previous studies have supported further training for healthcare professionals(23,103) (see section 3.7) and participants in our study were keen for local face to face postgraduate training in ACP. It was also proposed that starting training at an earlier stage would be of benefit, with education of GP trainees on ACP as well as establishing ACP as part of medical school curricula.

9.7.2 Routine use of ACP: *'It needs to be just part of what we do with patients.'*

Guidance (RCP, NEOF, see section 5.3) recommends the routine use of ACP in primary care, a proposal supported in the literature by previous studies.(41) Our participants also favoured this as a means of increasing the use of ACP, with standardization and routine use making it seem more 'normal'. In aiming to make more use of ACP, it was suggested that there should initially be particular focus on appropriate groups of patients, such as those who were identified as requiring frequent

ⁱ Internet searches failed to identify any evidence of these issues having been discussed in an episode of EastEnders, or indeed in other British television soap operas such as Coronation Street or Emmerdale, or in the radio soap opera The Archers, which was mentioned by members of the focus group. Reference was found to an episode of the medical drama Holby City (Season 11, Episode 44, aired on BBC One, August 2009) involving an advance decision to refuse treatment in the form of resuscitation. In the US, a public education project funded by the Robert Wood Johnson Foundation resulted in three episodes of the medical drama ER addressing end of life issues and ACP, with one particularly focusing on the importance of having an ACP in ensuring that end of life wishes are followed at the end of life. A report of this project can be found on the Foundation's website. Available from:
http://www.rwjf.org/content/dam/farm/reports/program_results_reports/2006/rwjf65530

visits, a suggestion similar to that of NCoLCP guidance(176) that ACP should be considered in cases of multiple hospital admissions; participants also believed that time should be set aside for ACP in routine practice. However, while inclusion of requirements for ACP in the Quality and Outcomes Framework as suggested in RCP guidance (see section 5.3) might well be expected to increase the frequency of its use, one GP specifically requested that this strategy should not be used, due to a belief shared by other participants that ACP was not necessarily suitable for everyone.

Various studies have highlighted the importance of information sharing in ACP,(88,103) (see section 3.7) and guidance advocates the appropriate sharing of ACPs (BMA, GMC, RCP and NCoLCP, see section 5.3). Our study demonstrated a wish amongst primary care professionals for standardization of documents for ACP, with strong support identified for this suggestion in our survey. Several participants expressed concerns about recognition and transferability of ACP, with various mentions in interviews of a brief pro forma, and forms that 'look like a legal document' and are likely to be accepted by other healthcare professionals, particularly out of hours and emergency services. Participants in our study were aware of a variety of documents being available and most Practice Managers felt that documentation was available in their practices to help them in carrying out ACP. Guidance suggests a combination of currently available documents may be most useful,(172) but, despite documentation being generally considered essential to ensure that wishes are followed,(20) there exists no statutory form for ACP in the UK, either for advance statements of wishes or for advance refusals of treatment (see section 2.4.1). In fact, at least one commentator(202) clearly predicted the problem of lack of standardisation with statutory forms at the time that proposals were being made for legislative provision for ACP, highlighting in particular the need for documentation with a uniform appearance and structure in order that professionals can be confident in their validity ensuring that wishes are followed in emergencies.

Participants also felt that in facilitating effective routine use of ACP, advantage should be taken of the availability of other healthcare professionals, with several suggestions that Practice Nurses might be an appropriate group to help introduce ACP into primary care populations; in fact the lay people we discussed this with felt that, while GPs might be ideal, it did not matter unduly who suggested ACP, as long as someone brought the subject up with patients, with one participant stating that she might prefer to discuss

ACP with a nurse. The fact that previous studies have successfully used trained ‘non physician’ facilitators(55,61) (see sections 3.5.2 and 3.5.3) would support this.

9.7.3 Family involvement: *‘The best discussions are where the family are aware...’*

Previous research has demonstrated support of professionals and families for greater involvement of families in ACP with evidence of benefit in helping clarify documentation,(101) increasing likelihood of wishes being followed,(99) and a belief that involvement of family helps to reduce conflict and disagreement(33,38) (see sections 3.3.2 and 3.7). Our study confirms these findings with a belief among lay people and clinicians that family members often have a great deal to offer in this process in terms of assistance and that ACP is likely to be more useful and effective when families are involved.

In addition, involvement of families is likely to be key in carrying out ACP in patients of diverse cultural backgrounds, where evidence from the literature suggests(138,139) (see section 4.5) that there may be much greater focus on the family and community as a decision making unit. Evidence of inequalities in the availability and uptake of ACP in the literature is complex (see section 4.6), with ethnicity by no means alone in a range of factors involved. However, ethnicity is nevertheless likely to play a significant role and many GP practices will provide services for populations including a variety of ethnic groups. While acknowledging the dangers of categorizing patients by culture or ethnicity, uncovering important differences in decision making styles will be essential to developing an understanding of patients’ needs with regard to ACP, and family communication may often be key in this process.

Given the apparent importance of family involvement therefore, the confirmation by lay people in our study of the evidence in literature(36,41) (see section 3.6) that relatives are uncomfortable with discussion of ACP, might argue more strongly for early and effective family engagement in ACP in order to allow the process of discussion within the family to take place.

9.8 Effects of participants’ characteristics on responses

Overall, this study found minimal association between participants’ characteristics in terms of age, sex and length of time working in their current role and their responses in the questionnaire survey, but a small number of statistically significant relationships may require further explanation (see section 8.3.4).

Previous work has demonstrated significant differences in primary care practice style by age of General Practitioner,(203) and it seems perhaps unsurprising that older professionals as well as those who have more years of experience in their professional role feel less of a need for training in ACP. GPs are known to attract patients closer to their own age, (203) so older GPs, in addition to having greater experience over time, may see proportionally more patients for whom ACP is relevant.

Although we did not identify any statistical association between declared experience of ACP and age or years in role, greater experience in professional role might logically result in greater confidence in dealing with the difficulties inherent in use of ACP, therefore explaining the relationship identified between those with more years in their current role and less agreement that ACP is difficult to apply in practice.

Finally, several studies have investigated the effect of GPs' sex on their practice,(204,205) with evidence that female GPs gain greater satisfaction for example from the psychosocial aspects of practice and from developing their relationships with patients. It is possible that their focus on the area of interpersonal relationships results in female GPs gaining a greater awareness of the potential complexity of capacity assessment and of ACP generally, resulting in them expressing a higher degree of caution in such assessments as well as perhaps a greater interest and desire for further training.

9.9 Key interpretative themes

As the previous sections have shown, consideration of the findings of this study have allowed a detailed understanding to develop of the use of ACP in primary care in the UK, confirming and extending the findings of previous studies and demonstrating their applicability to this particular setting.

It is also possible, taking a broader approach to the data, to identify a small number of key interpretative themes, which help to establish what may be seen as some of the central messages of this research:

9.9.1 *Empowerment*

Patient empowerment, in the sense of giving people the ability and opportunity to make important decisions about their future care, establishing a degree of self determination or control over what might happen to them that would otherwise be unattainable, may reasonably be considered to be central to the concept of ACP. Closely linked is the high

level of respect in current medical practice for the concept of autonomy, considered to include protection of the ability of individuals to make decisions about themselves. ACP seems to provide a means of supporting both these ideals, enabling patients to make decisions about their future care, and continuing to respect those decisions once the patients have lost capacity. As a consequence, healthcare policy has tended to provide strong support for the use of ACP (see sections 4.4 and 5.2).

Our study confirmed this, with participants placing particular emphasis on patient choice and control in terms of benefits of ACP (see section 8.1.3.7). The importance of ACP in providing an element of control over future care extended to a feeling of empowerment amongst lay members of our focus group, apparent simply when talking about ACP, with forceful wording used and the development in the course of discussion of a sense that ACP was a right that patients were entitled to expect (see sections 8.2.3.1 and 8.2.3.5).

While the importance of ‘empowerment’ as a key element of ACP was undoubtedly supported in our study, this data also provides evidence of contrasting beliefs relating to loss of control resulting from ACP. One GP, for example, expressed a fear that ACP might potentially be ‘disempowering’ (see section 8.1.3.11), by which she referred to the possibility that some patients might feel a loss of control in making ACPs, in having ‘given the control away’. Perhaps the potential for coercion or abuse of ACP (see sections 2.6 and 4.6), relating both to vulnerable people with capacity and those lacking capacity, may make such fears justified. However, it seems that patients are not the only participants in the process of ACP who may experience feeling of ‘disempowerment’: other GPs in our study (see section 8.1.3.8) described a sense of loss of control from the point of view of clinicians when carrying out ACP, where doctors, used to having a significant degree of control over healthcare decisions, may find it difficult to hand over this responsibility to their patients.

9.9.2 *Consent*

An ongoing debate exists in the literature regarding the difficulties involved in prediction of future wishes for the purposes of ACP, with evidence from previous research of the significant problems people have in judging future emotional states in general (see section 4.3) as well as wishes about future medical decisions specifically(109). Related work has discussed the relevance of a theory of ‘personhood’

to the binding of ‘future selves’ to the decisions of ‘current selves’ by means of ACP (see section 4.3).

Participants in our study demonstrated a high degree of appreciation of these issues. Highlighting the difficulties involved in accurately predicting future wishes for the purposes of ACP (see sections 8.1.3.11 and 8.3.3.6), they also recognized the role of capacity in determining patients’ ability to participate in the process of ACP (see section 8.1.3.5). A significant related concern therefore was the availability of opportunity for patients to change their minds about decisions made as part of ACP after they were formally documented (see sections 8.1.3.11 and 8.3.3.6), with some participants also worried about the position of patients who had lost capacity to make decisions and were bound by previous refusals of treatment, who might now appear happy to receive those treatments.

In addition, clinicians in our study identified difference between clinical opinion and patients’ decisions in ACP (see section 8.1.3.8) as a potential source of difficulty for professionals carrying out ACP. Seen alongside description in the literature (see section 4.4) of a belief amongst some professionals that patients do not always have the ability to make the decisions necessary for ACP, and of a predominance of physicians’ values in some decision making, this might raise doubts about the degree to which consent is respected by professionals as an essential element in carrying out ACP. Furthermore, ongoing funding related problems in healthcare provision with consequent rationing of care and restriction of services, with criticism of the true availability of some of the choices offered to patients in terms of care and treatments (see section 4.4), lead to further questions about the reality of informed consent regarding these decisions.

Together, these issues raise important questions about the extent to which ACP can be seen to be a truly consenting process for patients. Perhaps contributing to concerns expressed by one participant regarding ‘disempowerment’ of patients in the giving away control over future care, consent and the stability of decision making processes in ACP should therefore be considered to be another central theme, and one with fundamental implications for the validity of ACP as a concept.

9.9.3 *Coercion*

Also of great importance would seem to be the theme of coercion, with the comments and responses of participants in our study (see sections 8.1.3.11 and 8.3.3.6) highlighting the significant concerns previously expressed in the literature (see section

4.6) relating to the wide range of potential motives for the exertion of undue influence on patients in the making of ACPs.

Clinicians displayed a high degree of sensitivity to these difficulties, with recognition of the complex interplay of motives of those making ACP as well as those advising and assisting them in this process (see sections 8.1.3.11 and 8.1.4), and of the great difficulties presented to professionals in attempting to assess and uncover such coercive influence.

While readily acknowledging these difficulties, no mention was made by participants of the existence of safeguards against coercion or other abuse of ACP, perhaps suggesting a limited awareness of the potential courses of action available to professionals who have concerns about such issues. In fact, while safeguards exist, these suffer from some significant limitations (see section 2.6) with in particular a surprising apparent lack of anticipation in legislation for the problem, readily recognized by our participants, of a potentially hazardous mixture of vulnerable patients and allocation of financial decision making authority. Apparent disincentives in the form of fees for reporting concerns are likely to compound these problems.

9.10 Challenges and limitations

9.10.1 *Empirical challenges*

Although initial application for ethical approval of the study presented some challenges for BH as a new researcher, the application went relatively smoothly, with the process taking approximately ten weeks including completion of some minor amendments to the research subject information sheets requested by the Committee. However major complexity arose from the need to seek independent approval of the study from each of the eight individual Primary Care Trusts (PCTs) and one Mental Health Trust in East Anglia where the research was to take place.

Communication with the Research and Development (R+D) departments was problematic, with difficulty identifying persons with relevant responsibility and seemingly little experience in many of the departments in dealing with small 'non portfolio' studies of this kind. Unfortunately, this came at a time of substantial change within the NHS, with several PCTs merging, dissolving and reforming during the course of the study. As a result of these changes, communication became more complex, with increasing difficulty in identifying those responsible for overseeing the

study. In several cases administrative posts remained unfilled for extended periods of time resulting in substantial delays: a gap of six months, for example, occurred between application for R+D approval to interview four Consultant Old Age Psychiatrists, who had in fact all already agreed to participate via an existing professional contact of BH.

Further administrative delay was encountered in developing the questionnaire survey. Although referred to in the initial application, it later became clear that development of the questionnaires was viewed as a 'substantial amendment' to the study, necessitating application to the Research Ethics Committee for approval, followed by application for approval from the Research and Development Department of the area where the survey was to be carried out; this process again took approximately ten weeks.

As has been described in previous sections (see Chapter 7, particularly sections 7.3.3, 7.4.3 and 7.5.3), recruitment presented a major challenge at each stage of the study, with consequent significant impact on the quantity of data collected, as well as arguably on the quality of that data, and therefore on the subsequent analysis possible.

There are likely to be a number of reasons for this recruitment difficulty. For example, workload associated with organizational change within the NHS might potentially have contributed to the lack of inclination amongst GPs and other healthcare professionals to commit to sparing the time either to take part in interviews or complete questionnaires; Practice Managers, who may have reviewed invitations prior to other professionals seeing them, may, at a particularly stressful and busy time in UK primary care, have been reluctant to pass invitations on, or at least presented them in a less than positive light.

The poor response from relevant charities in providing subjects for a focus group was surprising. In developing the study, it had seemed logical to approach relevant national bodies to provide interested contacts for discussion of interview findings. However, the significant involvement of these charities in large, funded research projects may have reduced their capacity to assist with our small study. It is possible that a more local and personal approach might have been more successful; it was essentially such an approach, making use of contacts through the University, that enabled the focus group to take place. Many GP surgeries now have Patient Participation Groups formed of patients who volunteer to meet and offer their perspective on a variety of aspects of the running of the surgery. In retrospect, perhaps use might have been made of these groups in recruitment for focus groups, with the possible result not only of generating more interest in the focus groups but also of gaining data more directly relevant to the other

parts of the study by involving patients potentially even registered at some of the practices where healthcare professionals were interviewed or subsequently involved in the questionnaire survey.

In general, a more personal, and persistent, approach to recruitment at all stages of the study might have been more successful, with personal visits to surgeries by BH to introduce the study, and perhaps the offer of brief educational sessions about ACP for the practice team. As a new researcher, BH may have lacked assertiveness in seeking participation of clinical colleagues, with a degree of reluctance to impose on their time. This reluctance was likely compounded by the fact that a quite restrictive plan was originally agreed with the Research Ethics Committee, which limited the number of approaches to be made to potential participants and the means by which these were made. Experience of the slow and bureaucratic process of ethical review strongly discouraged further subsequent approaches to the Committee for amendments to these limitations, which might have enabled more successful recruitment of research participants.

9.10.2 *Limitations and generalizability*

In a study of this size, focusing on a small sample in a specific area of the UK, limitations in scope mean that findings may not necessarily be generalizable to wider populations;ⁱⁱ a number of aspects of this study might have implications for generalizability of the findings.

Despite difficulties in recruitment, the completed study succeeded in involving participants in both individual interviews and the survey from a relatively broad spread of practices with a variety of list sizes and located across urban and rural areas. Participants themselves were from an age range that was likely to be representative of the region, although there was an unrepresentatively higher proportion of female to male participants.

However, overall numbers were small, and with the vast majority of participants GPs, there was limited representation of the views of other healthcare professionals. In

ⁱⁱ These remarks notwithstanding, when BH recently presented some of the findings of this study at the 2013 conference of the International Society of Advance Care Planning and End of Life Care (ACPEL), in Melbourne, Australia, an international audience expressed considerable interest, with comments describing a very similar experience of ACP in primary care in other countries, particularly Australia and New Zealand.

addition, although the focus group intentionally included interested parties rather than a wide demographic, the similarity in age, background and interests, and the fact that all lay participants were women, meant that their views might not be considered representative of wider populations.

It is likely that those that participated were those that are interested in the concept or use of ACP, perhaps making their views less generalizable. However the data suggest that those who chose to participate were not necessarily those that were knowledgeable about ACP, and in fact several GPs mentioned when interviewed that they had agreed to participate specifically in order to learn about ACP.ⁱⁱⁱ Nevertheless, lack of knowledge about ACP might also influence the views of participants, with it possible that their thoughts about ACP might change were they to have more experience of its use.

Within our sample, a greater proportion of participants for both interviews and survey were from the county of Norfolk than from other areas. While it is likely that a change in recruitment method resulted in this difference in the survey, it is possible that University linked teaching practices were more interested in participating in research generally, and felt a greater attachment and perhaps obligation to take part. However, with a slightly older general population,^{iv} it is also conceivable that primary care professionals in Norfolk might be expected to have greater exposure to the use of ACP than those based elsewhere.

Our interviews with clinicians reflect the participants' own accounts of their professional and personal experiences of ACP with respect to the primary care environment. Although strengthened by quantitative data from the questionnaire survey, as well as the scrutiny of lay input in the focus group, these results may not necessarily represent the views of a wider population or describe actual practice or the experience of patients and families. A more definitive picture of this would require the involvement of families and patients in the study.

ⁱⁱⁱ This occurred on two occasions, with these comments taking place during introductions prior to the digital recorder being switched on.

^{iv} 2011 Census data (England and Wales) suggests a slightly higher proportion of population over the age of 65 years in Norfolk (22%) compared with the East of England (18%) and England (16%). These data were obtained from the Norfolk Insight website. Available from: <http://www.norfolkinsight.org.uk>

9.11 Implications for ACP in primary care

9.11.1 *Education and publicity*

Participants in this study highlighted a need for greater publicity in ACP, aiming to raise awareness of the concept and promote the use of ACP to the general population. Primary care could potentially offer a very significant contribution to this process, with GP surgeries arguably an ideal environment for activity of this kind, with access to large numbers of patients on a regular basis, and professionals with a detailed knowledge of and longstanding relationship with their patients in an excellent position to suggest, discuss and carry out ACP. Broader public health promotion is clearly also needed however, and evidence of the effectiveness of community wide educational programmes for ACP,(55) makes participants' suggestions regarding television and radio approaches to publicity on ACP particularly valid in this context; perhaps also emerging research(102) on the use of the Internet and social media may be of significant potential benefit in promotion and education about ACP.

However, as participants in our study readily acknowledged, our findings also demonstrate an urgent need for education of professionals, with a surprising and significant lack of knowledge, understanding and experience of ACP evident in the primary care setting. Participants highlighted the important role of primary care professionals in the ACP process, with one pointing out that they should be seen as the 'experts' on ACP from whom patients can seek information and advice. As the 'first port of call' for ACP therefore, it will be essential that the knowledge base is solid and that professionals have the core competencies, as outlined in guidance,(176) necessary to provide this information and advice accurately and effectively.

Apparently linked to their lack of knowledge, a number of participants displayed hesitancy and uncertainty about legislation and legal aspects of ACP; discussion with lay people suggested that uncertainty about legal matters might extend to other areas with overcautiousness in relation to confidentiality damaging communication with families. When questioned about another legal aspect of medical practice, capacity assessment, in relation to ACP, most interview participants seemed to have a grasp of the legal requirements, but this was not generally discussed in detail, and those surveyed showed low confidence in assessment of capacity specifically for ACP. It is therefore arguable that there might be a more general lack of knowledge amongst professionals

and perhaps a related unwillingness to engage in anything perceived as associated with the law or legislation.

One participant (see section 8.1.3.10) described experience of fundamental conceptual misunderstanding of ACP by other healthcare staff, who were reportedly reluctant to provide any treatment to a patient who had a ‘do not resuscitate’ order in place. If representing a more generalized behaviour amongst healthcare professionals, this would clearly have very serious implications indeed for the use of ACP, compounded by participants’ concerns about a perceived association between ACP and euthanasia or assisted suicide, as well as the potential for ACP to be used in saving healthcare costs. The recent controversy surrounding the Liverpool Care Pathway has highlighted the way in which an intervention intended to be of significant benefit to patients can become, as a result of lack of understanding and inappropriate implementation and use, associated with intentional hastening of death; it is not difficult to see how the concept of ACP could be similarly misunderstood unless decisive action is taken to address such interpretation.

9.11.2 ‘Normalization’ of ACP and increasing ‘routine’ use

Participants in this study expressed themselves in favour of increased use of ACP in primary care, with mention in interviews of making it a more ‘normal’ part of care, and support in the survey for routine use in certain medical conditions and at the time of new significant diagnoses. Both the literature(41) and guidance on ACP (RCP and NEoLCP, see section 5.3) support the use of ACP as a ‘routine’ part of care, and one guideline(172) advocates its integration into the Quality and Outcomes Framework (QOF) as a means of achieving this.

Establishing ACP as part of QOF, or indeed as Directed or Local Enhanced Services (DES or LES),^v would certainly be expected to be a way of increasing the routine use of ACP in primary care. However at least one GP was strongly against this, pointing out that ACP is simply not appropriate for all patients and stating forcefully that the process should not be made a requirement of the QOF. Indeed, a number of strong arguments

^v These terms describe extra services which GP practices agree to offer on top of the core services they are contracted to provide, and for which they receive additional remuneration. Payment of such remuneration would usually be subject to achievement of a specified target in terms of achievement of the objective of the enhanced service, which for ACP might for example involve carrying out or documenting ACP with a certain percentage of patients within target groups.

exist as to why incentivizing professionals to carry out ACP with patients may not be an appropriate way of increasing its use, and furthermore may be seriously detrimental to public perception of the process.

There is no doubt that the discussion of ACP is a sensitive issue, with evidence in the literature (see section 3.6) as well as our study (see section 8.1.3.8) of discomfort with discussion on the part of both patients and clinicians, and the process is likely to be appreciated very differently by different individuals. It seems likely that it is most effective when carried out in a targeted manner, tailored to individual patients' needs, making directed approaches to its implementation such as QOF or enhanced services seem unsuitable. Not only may such programmes not be successful in that enhanced services do not necessarily achieve universal coverage, but also, as perhaps suggested by evidence in our study (see section 8.1.3.2) and others(33) of conceptual misunderstanding of ACP, they may lead to a 'tick box' approach to ACP failing to address patients' real needs and thus failing to achieve development of useful and effective ACPs in the same way as some previous studies.(50)

Perhaps most importantly, however, bearing in mind concerns expressed by some of our participants (see sections 8.1.3.11 and 8.3.3.6) about financial drivers in ACP, it will be crucial to avoid any possibility of misinterpretation; the apparent existence of 'reward payments' for use of ACP could potentially be extremely risky. As discussed previously (see section 4.6 and 4.7) one of the most concerning aspects of the Liverpool Care Pathway controversy, and certainly one that vividly captured the imagination of the public and media, was the possibility that financial incentives had been provided for the purpose of increasing its use. Alongside beliefs that the pathway might be used as a means of deliberately hastening the death of patients, the possibility that payments were being made to healthcare services for use of the pathway as a means of saving costs in end of life care had dramatic implications; for ACP to continue to be a valuable and useful process for patients, it will be essential that any similarly controversial association with financial incentives be avoided.

This is not to say that encouraging the use of ACP more frequently with patients in primary care as advocated by our participants is in itself problematic. However, it is clear that great care will be needed to ensure that this is done in a sensitive manner to ensure appropriate increase in use of patient centred ACP while avoiding potentially negative associations.

9.11.3 *Diversity, individualized approaches and the reality of choice*

In addition to other widely recognized barriers such as professionals' discomfort with discussion(33) and lack of time,(93,94) this study highlighted the importance of inequalities in the availability and accessibility of ACP to patients, where a significant factor may be cultural differences in ethical frameworks and understanding of ACP. Research has already demonstrated complex variation in attitudes to ACP across diverse populations(136,137) (see section 4.5); in multicultural societies it will be particularly important for professionals to be aware of these issues.

Perhaps these issues suggest a need therefore for a more tailored approach, targeting specific patients or groups of patients in a stepwise manner, taking advantage of the continuity offered by primary care, with involvement of family to help establish the 'knowing relationships' described in the literature(38) and by some of those interviewed in this study, where a genuine understanding is developed between patient and healthcare professional regarding how they might be cared for in the case of loss of capacity, which can then be appropriately documented and shared.

However, in order for this to be of any significant value, the infrastructure must be in place to enable implementation of patients' wishes. Commentators(106,129) (see section 4.4) have criticized the illusory nature of autonomy in healthcare in the sense that rationing and funding difficulties compromise the choices available to patients, and this is certainly applicable to ACP. With many patients for example likely to choose to remain at home at the end of life, it will be essential to ensure that appropriate increases in funding and staffing levels of community services are made available to support this.

9.12 Future research

This study investigated the experience and use of ACP amongst a small number of primary care clinicians, mostly General Practitioners, in GP practices in the East of England. Acknowledging the particular limitation of this study in terms of number of participants, extension of this work, ensuring greater generalizability, would require the involvement of a larger study population, with a greater proportion of other primary care professionals, including Practice Nurses, Community Nurses and GP trainees, as well as expansion of the geographical location of the study to encompass a wider area. Having developed a useful understanding of the experience of clinicians of ACP, it would be very valuable to seek the views of patients on this subject, and given the findings in this study and previous research of the central importance of family

members in ACP discussions and decisions (see sections 3.3.2 and 3.7), involvement of families and carers in future studies would seem likely to be particularly advantageous also.

A specific example of an area that might benefit from further investigation from the particular perspective of patients, families and carers, is the question of stability of decision making in ACP and the implications of patients' ability to change their mind about decisions made as part of ACP (see sections 8.1.3.11 and 8.3.3.6). A prospective study could be designed, with both qualitative and quantitative elements, following a group of patients over the course of a number of years to seek information on patients' likelihood of changing their minds about these decisions as well as their ability to do so in reality and the impact of this on their future care. This might involve interviewing patients, families and carers about their wishes at various stages, talking to bereaved families about whether patients changed their minds about decisions, and comparing these with their documented wishes in ACPs, as well as correlating these with the same patients' actual outcomes in terms of the care and treatments they received.

Our study has demonstrated a particular need and support amongst primary care clinicians and lay people for greater promotion of ACP to the general public as well as further postgraduate, and potentially undergraduate, training for professionals in this area. With previous studies also providing support for public and professional educational programmes (see section 3.7), this should be a particular target for further work, with research looking at ways in which people can be educated effectively about ACP, particularly in the primary care environment, with development and evaluation of new promotional and training interventions.

One condition felt by many of our participants to be of particular importance in ACP was dementia (see section 8.1.3.9), sufferers from which are of course at significant risk of future loss of capacity and therefore arguably appropriate targets for use of ACP. Perhaps especially relevant in primary care, given current focus on early diagnosis and the problems acknowledged by clinicians in our study of patients losing capacity before having the opportunity to participate in ACP, the small number of previous studies that have investigated this area have highlighted the lack of ACP in patients with dementia^(76,77) and called for more research to establish ACP as an evidence based part of routine dementia care^(80,81) (see section 3.5.5). Difficulties in decision making with people with dementia, and the sensitive nature of ACP, as well as the suggestion that approaches to ACP that are more individually tailored to patients or conditions may

be more effective (see section 3.7), might support a need for further investigation aiming to develop specific interventions or approaches for the introduction and use of ACP with patients with dementia. A study might therefore be conceived to develop, by means of detailed analysis of existing approaches to ACP and careful consultation with relevant parties including patients, families and primary care professionals, a tailored framework for carrying out ACP with patients with dementia in the primary care environment. This might combine programmes of publicity and education on ACP both for patients, families, carers and primary care professionals, with a flexible model for carrying out ACP with patients with dementia, as well as a form of documentation or means of recording ACP appropriate to such patients. Following testing and refinement of this model for ACP with patients in primary care, the existence of a robustly developed approach to ACP in dementia might allow further important work to take place, investigating key outcomes in terms of effects of ACP on patients' future care and treatment to identify conclusively the place of ACP in dementia care.

Finally, this study has also highlighted a need for research in a related area, outside the field of ACP. Primary care professionals' lack of knowledge regarding the legal basis of ACP, lack of confidence in assessment of capacity, and apparent apprehensiveness about legal matters generally suggest a need for fresh evaluation of these areas. With an ever increasing role of legislation in medical practice, and continued misunderstanding by public and professionals, compounded by misrepresentation in the media, the importance of medical professionals' knowledge of and confidence in relevant legal issues cannot be underestimated. Studies exist looking at GPs' experience of complaints and litigation and its effect on their practice.(206,207) Investigation of the confidence and competence of primary care and other healthcare professionals in assessment of capacity under MCA 2005 criteria in a variety of situations might be a starting point for important new work looking into the legal knowledge of professionals more generally and its effect on patients' care.

CONCLUSION

This small study of advance care planning amplifies and extends the understanding developed in a varied existing literature to apply to the specific environment of UK primary care. Giving valuable confirmation that many of the findings of previous studies have application in this setting, it also highlights a number of issues of particular relevance to primary care professionals.

Findings demonstrate a higher than anticipated degree of support for ACP, with widespread belief in its benefits in primary care seeming to outweigh the acknowledged significant barriers to its use. However, in stark contrast, knowledge of ACP was notably deficient, with surprising lack of awareness and detailed understanding of the concept, as well as limited familiarity with legal provisions and confusion about their application.

In developing a view of ACP in UK primary care, this study was particularly interested in the awareness and integration of guidance on ACP from the Royal College of Physicians. However, few were aware of the existence of this guidance and although participants indicated agreement with many of its key recommendations, there was no evidence that these elements were considered current practice. In fact, most professionals, despite their support for the concept, had very limited experience of using ACP with patients, taking a passive role in discussing ACP, with sometimes their only contact with ACP being where patients deposited completed documents to add to their records. In fact the lack of use of ACP despite clinicians' support may suggest the importance of barriers other than insufficient knowledge, with their apparent unease about legal matters perhaps contributing to a reticence to discuss ACP.

ACP in UK primary care therefore seems to succumb to some of the accusations of previous critics, in that despite support of national healthcare policy and existence of professional guidelines, as well as a general belief in the usefulness and benefit of ACP, both general public and professionals lack awareness of it, and even when they are aware, fail to make use of it.

However, a small number of examples of good practice were clearly evident, with some professionals describing more frequent use of ACP and a few practices involved in significant promotion of ACP activity within their patient populations. Furthermore, the views expressed amplified the suggestion in literature that primary care is an ideal environment for ACP, with participants highlighting the continuity of care offered in this setting, and showing a keen interest in improvements in ACP in primary care with evidence of their knowledge of, relationship with and concern for their patients, and

sensitivity to the importance of communication with patients, families and other professionals, suggesting their particular suitability for the role of facilitators of ACP.

This study puts previous research and professional guidance in the context of UK primary care and highlights areas for further development. Providing evidence of a strongly positive view of ACP in primary care in terms of professionals' support for its suitability to this environment, and utility and applicability to primary care patients, it nevertheless highlights some significant problems, central to which is the surprising lack of knowledge and understanding of professionals. However these problems are outweighed by the support of professionals, who are keen to make more use of ACP and are able to offer relevant suggestions for improvement.

In addition to establishing a sound basis for further necessary research in this field, it is hoped therefore that this work will help to inform strategies to improve the use of ACP, harnessing primary care professionals' evident enthusiasm to make ACP 'part of what we do' in UK primary care, but also with the potential to have wider application in primary care outside the UK.

One of the objectives of this study was to explore the specific perceived needs of UK primary care professionals in carrying out ACP, needs which were clearly identified in this research. In concluding, therefore, it seems appropriate to focus on these, making some final recommendations regarding the use of ACP in primary care practice:

1. There is a clear need for training of primary care professionals in the concept of ACP, as well as in legal provisions for its use, ideally supported by relevant professional bodies such as the Royal College of General Practitioners. Raising awareness of existing relevant professional guidance as well as promoting development of communication skills relevant to ACP, it will also be necessary to enhance professionals' understanding of the views of patients on ACP, particularly in terms of their willingness and desire to discuss these issues. This training should be established with a view to the education of professionals at the beginning of their careers, as well as with more experienced professionals.
2. A similarly pressing need seems to exist for public education on ACP, increasing general recognition and knowledge about its availability and the benefits and choices it offers, aiming to help alleviate the recognized inequalities in availability and uptake of

ACP. In the context of lay understanding of ACP, it will be particularly important to address any negative associations with, for example, assisted suicide and euthanasia or financial incentives, in a clear and sensitive manner to ensure continued support and positive perception of the concept. Linked to this is the continued necessity to improve public understanding of good and appropriate palliative care, especially following the recent Liverpool Care Pathway debacle. Involving a requirement for widespread and imaginative use of publicity, this is likely to require significant investment as well as strong political leadership in order to be successful.

3. There is evidence of a need for greater standardization of the process of ACP, particularly with regard to documentation. The lack of statutory forms for advance statements and advance decisions to refuse treatment is regrettable and this omission would ideally be rectified in legislation (clearer reference in the Mental Capacity Act 2005 to the concept of advance statements would also be advantageous). A key concern in primary care appears to be the availability and recognition of completed ACPs when needed in emergency and out of hours situations; standardization of documents, with improved communication and information sharing between professionals will be essential, perhaps with development of Internet based methods of sharing, as well as reviewing and updating, ACPs.

4. Primary care professionals need time for ACP as well as support and assistance in carrying out this process effectively with their patients. The possibility of involvement of professionals other than GPs in this process could be of substantial help, with Nurses and other health professionals potentially having more time for discussion of ACP, while continued input from GPs should provide the knowledge and expertise required to establish effective and relevant ACPs. Related to this, it will be essential that primary care professionals have the necessary support in the community to allow patients' wishes regarding future care, particularly with regard to place of care and avoidance of unwanted hospital admissions, to become a reality. This will clearly require recognition of the vital importance of community services, with continued development and investment.

APPENDIX 1

Publications and presentations

A1.1	Publications	219
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A1.1 Publications

1. Hayhoe B, Howe A. Mental capacity and the ability to participate in advance care planning. Submitted to the Journal of the Royal Society of Medicine: Short Reports. In review.
2. Hayhoe B, Howe A. Advance care planning under the Mental Capacity Act 2005 in primary care. BJGP 2011; 61: 528-529.
3. Aw D, Hayhoe B, Smajdor A, Bowker L, Conroy S, Myint P. Advance care planning and the older patient. Q J Med 2011; doi: 10.1093/qjmed/hcr209

A1.2 Presentations

1. Advance care planning in primary care in the East of England: putting guidance into practice? 4th International Society of Advance Care Planning and End of Life Care Conference. Melbourne Convention and Exhibition Centre, Melbourne, Victoria, Australia. 9-11th May 2013. Abstract: BMJ Supportive and Palliative Care. doi: 10.1136/bmjspcare-2013-000491.45
2. Advance care planning in primary care: ethical concerns. Primary care ethics conference. Royal Society of Medicine, London, February 2012.
3. Advance care planning in primary care: knowledge, views and experience. Society for Academic Primary Care Annual Conference 2011. University of Bristol, July 2011.
4. Advance care planning in primary care: helping patients extend their autonomy? Royal College of General Practitioners Annual Primary Care Conference 2010. Harrogate International Centre, Harrogate, October 2010.

A1.3 Poster presentations

1. Advance care planning in primary care: what do we need to learn? Royal College of General Practitioners Annual Primary Care Conference 2011. Arena and Convention Centre, Liverpool, October 2011.
2. Preserving autonomy? Ethical questions in advance care planning. Conference on Ethics of the Ordinary. Royal Society of Medicine, London, February 2011.
3. Anticipating mental incapacity: the case for advance care planning in primary care. The Society for Academic Primary Care Annual Conference 2010. University of East Anglia, Norwich, July 2010.

Appendix 2

The Mental Capacity Act 2005: ‘capacity’ and ‘best interests’

A2.1	Basic structure and provisions of the Mental Capacity Act 2005	221
A2.1.1	<i>‘Incapacity’ and ‘inability to make decisions’</i>	221
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A2.1 Basic structure and provisions of the Mental Capacity Act 2005

The Mental Capacity Act 2005 (MCA 2005) provides a comprehensive framework for decision making on behalf of incapacitated people and gives specific statutory description of the terms ‘incapacity’ (MCA 2005 s.2), ‘inability to make decisions’ (MCA 2005 s.3), and ‘best interests’ (MCA 2005 s.4).

The Act is founded on five ‘principles’ (MCA 2005 s.1): a person must be assumed to have capacity unless it is established otherwise, no one should be treated as unable to make a decision until ‘*all practicable steps*’ have been taken to help him, no one should be treated as unable to make a decision ‘*merely because he makes an unwise decision*’, any acts or decisions made on behalf of someone lacking capacity must be made in his best interests, and any such acts or decisions should be made in the way that is least ‘*restrictive of the person’s rights and freedom of action*’.

The MCA 2005 provides a special safeguard for people who lack capacity in the form of Independent Mental Capacity Advocates (IMCAs) who exist to support them when decisions need to be made, determining their best interests and advising on decisions made on their behalf. It also establishes a new Court of Protection, the jurisdiction of which is extended to allow it to make personal welfare decisions on behalf of people lacking capacity in their best interests, as well as to appoint ‘deputies’ to make such decisions (MCA 2005 s.15-21). In addition, the Act makes it an offence to ill treat or wilfully neglect a person without capacity.

Finally, the MCA 2005 gives formal statutory support for the concept of advance care planning, recognising anticipatory decision making in the form of advance refusals of treatment as well as advance statements of wishes, and giving legal standing to proxy healthcare decision makers in the form of Lasting Powers of Attorney.

A2.1.1 ‘Incapacity’ and ‘inability to make decisions’

Mental capacity is usually understood to describe the ability of people to make autonomous decisions. It is ‘time and decision specific’ and must be assessed for each decision to be made since a person who lacks capacity to make one decision may still be able to make another, or may be able to make the same decision at a different time. Furthermore, it cannot be established merely on the basis of age, appearance, condition or behaviour; a diagnosis of dementia, for example, does not equate with lack of capacity.(79)

Starting with the assumption of capacity, the two concepts ‘incapacity’ and ‘inability to make decisions’ defined in the MCA 2005 together form a new two part test for mental capacity (MCA 2005 s.2-3), based on the previously established common law test:

1. *A person lacks capacity if he is unable to make a decision because of an impairment of or a disturbance in the functioning of the mind or brain*
2. *A person is unable to make a decision if he is unable to:*
 - i. *understand the information relevant to the decision*
 - ii. *retain that information*
 - iii. *use or weigh that information as part of the process of making the decision*
 - iv. *communicate his decision (by talking, sign language or any other means)*

The Act particularly stresses the importance of providing people with assistance in communication before judging them to lack capacity. Simple language, visual aids, and sign language are mentioned, and the MCA 2005 Code of Practice (4.23) warns that only very few people should be treated as unable to make decisions on the basis of inability to communicate, including those who are unconscious, in a coma, or suffering from ‘locked in syndrome’.

A2.1.2 ‘Best interests’

The best interests principle intends that when making decisions for or affecting people who lack capacity every effort is made to ensure that each decision is as close as possible to how the person would have made it himself if he had retained capacity. The MCA 2005 gives detailed instructions as to how assessment of a person’s best interests should be carried out (MCA 2005 s.4). In particular, it requires that the following factors should be considered (MCA 2005 s.4(6)):

- a) *the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),*
- b) *the beliefs and values that would be likely to influence his decision if he had capacity, and*
- c) *the other factors that he would be likely to consider if he were able to do so.*

In addition, the views of a number of other people should be sought and taken into account in forming an assessment of best interests including (MCA 2005 s.4.7): anyone named by the person, anyone caring for the person or interested in his welfare, any donee of a lasting power of attorney granted by the person, and any deputy appointed for the person by the court.

Appendix 3

Colchester advance care planning document

Planning for your future care (Advance Care Planning)

A1.1

Colchester Hospital University NHS Foundation Trust,
Anglian Community Enterprise and St Helena Hospice

224

Colchester Hospital University
NHS Foundation Trust

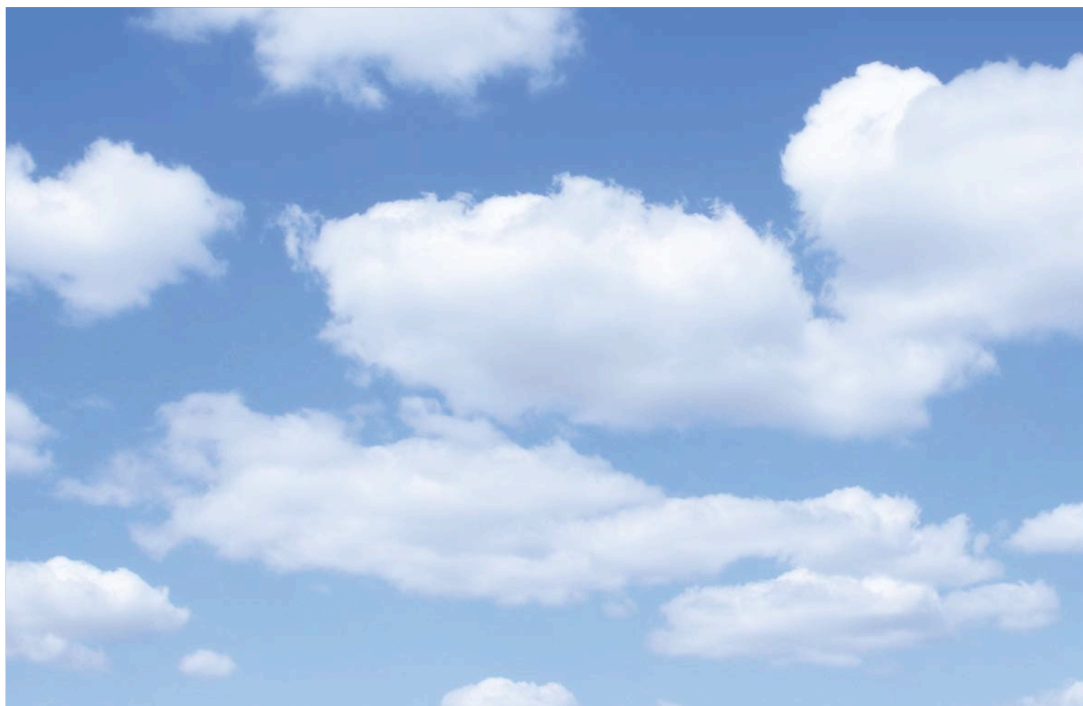


your local healthcare provider
gace
anglian community enterprise



St Helena Hospice
your time...your hospice

Registered Charity Number 280919



Planning for your future care (Advance Care Planning)

- Preparing for the future
- Assisting with practical arrangements
- Enabling the right care to be given at the right time

- **This document may contain a completed Advance Decision to refuse life sustaining treatment.**
- **You may wish to carry this document with you.**

Advance Care Planning

Advance Care Planning is very important.

By recording your preferences in this booklet it will help to ensure that your wishes are taken into account.

It will let health and social care professionals know what your wishes are and what is particularly important to you should you become too unwell to be able to tell anyone. We stress that any instructions in this booklet only come into force when you cannot make decisions at the time you are asked.

There is no set format for an *Advance Care Plan*, but it may help you to read the document *Planning for your Future Care – A Guide*.

Ask your doctor/GP for a copy, alternatively it can be found on the following web site.
<http://www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare>

However, you need to follow some formalities if you intend to refuse a treatment in advance.

The Mental Capacity Act 2005 has clarified the law on a number of matters and you will see this referred to throughout the document. The following link will make your rights clear.

<http://www.dh.gov.uk/en/SocialCare/Deliveringsocialcare/MentalCapacity/MentalCapacityAct2005/index.hm>

Or ask for the booklet: *Making Decisions...about your health, welfare or finance. Who decides when you can't?*

We have used the terms 'unwell' and 'illness' to cover a wide range of situations when you might not be able to speak up for yourself.

Please note that this booklet is not designed to be completed all at once. It can be filled in over a period of time, as and when you feel comfortable to do so.

This document is in three parts as shown on the next page.

The three parts

Part 1: About me

Page 5

This is where you give important information about yourself and what has happened in the past.

Part 2: Things that I want people to know

Page 7

This part will help people to know about important things that you may need help with.

For example, it could be about having your pet looked after, or instructions about financial issues.

Part 3: About my treatment preferences

Page 9

This part is to help people understand the way that you would prefer to be treated, should you need increased health care.

There is a special section where you can record your wish to refuse certain treatments (e.g. some people refuse blood transfusions on religious grounds). It may be a treatment that you want to refuse in all circumstances.

It is very helpful to record your full wishes on these issues.

There is a section for people who also want to refuse a treatment, even where that refusal could put their life at risk. This is your legal right if you want to do so.

Who to give your advance care plan to:

When you have completed your Advance Care Plan, decide who you would like to know about it. These people might include: relatives, friends, an advocate, your medical consultant, your general practitioner, your solicitor (if you have one) or anyone else you want to know about it.

Your GP and your consultant should be given a copy of the Advance Decision to refuse treatment if completed.

Advance Care Planning – how it can help plan your future care

Please note that this booklet is not designed to be completed all at once.

It can be filled in over a period of time, as and when you feel comfortable to do so.

Advance Care Planning (ACP) can help you prepare for the future.

It gives you an opportunity to think about, talk about and write down your preferences and priorities for your future care, including how you want to receive your care towards the end of your life. Anything can be included. If it is important to you, record it, no matter how insignificant it may appear.

Advance Care Planning can help you and your carers (family, friends and professionals who are involved in your care) to understand what is important to you. The plan provides an ideal opportunity to discuss and record in writing your views with those who are close to you. It will help you to be clear about the decisions you make and it will allow you to record your wishes in writing so that they can be carried out at the appropriate time.

Remember that your feelings and priorities may change over time. You can change what you have written whenever you wish to, and it would be advisable to review your plan regularly to make sure that it still reflects what you want.

The choice is yours as to whom you share the information with.

This booklet has been designed in consultation with patients and carers to assist you with the planning and recording of your preferences and wishes.

Statement of my wishes and care preferences

Print name _____ Date _____

I have written this following statement to help professional health and social care workers understand my wishes should I be unable to explain.

I would like this statement to be put in my medical and social care records (if it is not put on your records, it will be more difficult for medical staff to know that this statement exists). **YES / NO**

Signature: _____ Date of birth: ____ / ____ / ____

My address: _____

Part 1 - About me

I have these distinguishing features:

(It may be wise to include any distinguishing features in case you are ever found unconscious and cannot identify yourself).

My diagnosis/es:

A brief history of my illness:

How planning for your future can help

Planning my care

The main professional carer involved with caring for me is:

Print name: _____

He / she
is based at: _____

Tel number: _____

Please contact:

- Below are the names of people who know me well, like family members, friends, and advocates.
- They have given their permission to be contacted should I become unwell and I would like them to try to assist me if possible.
- I am happy for health and social care staff to discuss my condition and/or treatment with them.

Name	Relationship	Phone No(s) and/or other contact details

Please do not contact:

Should I become unwell and unable to make the decision for myself, I would **not** like the following people to be told.

Name	Relationship	Details

Part 2: Things that I want people to know

List here anything else with which you may need help should you become unwell.

For example, you may wish to include information about the care of your children and/or other dependants, information about your pets, about important work issues or financial affairs such as mortgages, bills, rent etc.

You may also wish to include other matters about keeping things going at home e.g. milk, papers, security etc. It will be helpful to name particular people who may be able to help with any of these.

The following additional things are important to me:

Things I want people to know

Things I want people to know

Other things that people need to know to help with my care:

(List things that are important to you, as part of your care).

Help with communication: (for example if you have hearing loss):**Diet:** (like needing halal or vegetarian food):**Medication or treatments for a medical or physical condition:**

(like diabetes or sight loss):

Allergies:

I have an Implantable Cardioverter Device (ICD).

Delete as appropriate

Yes / No

I have made a decision regarding this device for the future.

Yes / No

I wish to have this device deactivated when I approach the end of my life.

Yes / No

I have informed my main professional carer.

Yes / No**Religious or spiritual beliefs that may affect my care:**

Name of religious leader:

Contact details:

Cultural requirements for yourself or your family when confronting serious illness:**Other:**

Part 3: About my care and treatment preferences

You may wish to say where you would like to be cared for if it is not suitable for you to stay at home, you may have already completed a Preferred Priorities of Care (PPC) document, in which case we suggest you keep a copy of the PPC with this document.

There may be other preferences that you wish to document below, as your preferences of care must be taken into account by health care professionals making decisions about you should you be unable to tell them at the time.

With regard to treatments and care, you are reminded that you can only express a preference, you cannot demand them.

Any specific refusals of treatment can be recorded in the next sections.

If I become unwell, my preferences regarding care and treatment are as follows:

Statement of my wishes and preferences

Appointing Someone to Make Decisions for You

There are some situations when you might anticipate that you will deteriorate mentally (e.g. dementia). If this is the case you may well decide to ask a specific person to undertake the responsibility for making decisions for you if and when you are unable to do so yourself. That person is given Lasting Power of Attorney (LPA).

The person chosen can be a friend, relative or a professional. More than one person can act as attorney on your behalf.

Lasting Power of Attorneys are exclusive to you and the amount of power and limits of that power are decided by you.

There are two types of Lasting Power of Attorney:

Property & Affairs Lasting Power of Attorney

- This LPA gives another person (your attorney) the power to make financial decisions for you e.g. managing bank accounts or selling your house. Your attorney has the power to take over the management of your financial affairs as soon as the LPA is registered with the Office of the Public Guardian, unless the LPA states that this can only happen after you lose the capacity to manage your own financial affairs.

Since 1 October 2007 the Enduring Power of Attorney (EPA) has been replaced by the Property and Affairs LPA. However, valid EPAs that were already arranged before 1 October 2007 will still stand.

Personal Welfare Lasting Power of Attorney

- This LPA allows your attorney to make decisions regarding your health and personal welfare e.g. where you should live, day to day care or about your medical treatment. It only comes into force if/when you lose the ability to make these decisions for yourself and is only valid once it has been registered with the Office of the Public Guardian.

LPAs must be registered and there is a cost implication for registration. The forms can be completed and registered without the input of a solicitor, but this can be a complex procedure without guidance. If legal help is sought, then there may be a cost attached.

Advance Decision Making

An Advance Decision (AD) is different from your preferred priorities for care as it is a formal, legally binding document which allows an individual to refuse certain treatments.

It does not allow for a request to have life ended and cannot be used to request medical treatments.

An Advance Decision is very specific and is used in situations when particular treatments would not be acceptable to someone. An example would be if a person had a severe stroke which resulted in swallowing problems. If the thought of being fed by alternative methods such as tube feeding was not tolerable then this could be documented formally as an Advance Decision.

In order to make an Advance Decision advice should be sought from someone who understands the complexity of the process such as a member of your health care professional team, your GP/Doctor, or a solicitor.

An Advance Decision can be written or verbal, but if it includes the refusal for life-sustaining treatment, it must be in writing, signed and witnessed and include the statement '*even if life is at risk*'.

An Advance Decision will only be used if, at sometime in the future, you lose the ability to make your own decisions about your medical treatment. To be valid, an Advance Decision must be made before you lose your ability to make such decisions. You can change your mind about your Advance Decision, or amend it at anytime, provided you are still able to do so.

Further Information

www.direct.gov.uk

www.endoflifeforadults.nhs.uk

www.ageuk.org.uk

ESSEX Mental Capacity Act information:

www.essex.gov.uk/health-social-care/carers/pages/mental-capacity-act.aspx

Advance Decision Making (part 1 of 5)

Your name:

Your date of birth:

You will need 4 copies of this completed form:

- One for you to keep. ☐
- One for your GP to keep with your records. ☐
- One to be kept with someone who you wish to be consulted about your treatment should this ever be necessary (eg next of kin, solicitor). ☐
- One to be kept with Palliative Care Team, Community Palliative Care Nurse/Hospice Team/District Nurse/Mental Health Team and Care Home as appropriate. ☐

All forms should be signed by at least one person who is not a close relative or expecting to benefit from your will e.g. health care professional.

I also have an Advance Statement of wishes and preferences for my care.

Yes / No

[See page 5](#)

Advance Decision Document (part 2 of 5)

If I become unwell I would like the following contacts to be involved if it ever becomes too difficult for me to make decisions for myself.

Contact 1. Name: _____

Relationship to you: _____

Telephone: _____

Address: _____

Do they have Lasting Power of Attorney? **Yes / No**
(If yes please state which type?) _____

Contact 2. Name: _____

Relationship to you: _____

Telephone: _____

Address: _____

Do they have Lasting Power of Attorney? **Yes / No**
(If yes please state which type?) _____

To my family, my doctor and all other persons concerned this Advance Decision is made by me:

Full Name: _____

Of (address): _____

I am writing this at a time when I am able to think things through clearly and I have carefully considered my situation. I am aware that I have been diagnosed as suffering from:

Advance Decision to Refuse Treatment

Advance Decision Document (part 3 of 5)

I declare that if I become unable to participate effectively in decisions about my medical care, then and in those circumstances, my directions are as follows (only sign the sections you feel are applicable).

1. Any distressing symptoms are to be controlled by appropriate treatments aimed at keeping me comfortable.

Signature: _____

2. I am not to be subjected to any medical interventions or treatment listed below.

I understand that such treatment may be aimed at prolonging my life and I wish to refuse them **even if my life is at risk**.

Signature: _____

Examples:

I do not wish for an attempt for my heart and lungs to be restarted if they stopped functioning. (Cardiopulmonary Resuscitation)

- I do not wish to be artificially fed or hydrated.
 - I do not wish to receive antibiotics for a particular infection (please state).
 - I do not wish to receive Non-invasive Ventilation (NIV) if my breathing becomes more difficult.
- (Please state your wishes in the box below / on a separate sheet if necessary)

Treatment to be refused (e.g, stoma formation, surgery) If you wish to refuse resuscitation please also ask your doctor about a specific DNACPR form - see page 19.	Reasons and circumstances (see examples above)

Advance Decision Document (part 4 of 5)

This is my Advance Decision to refuse treatments. It may include life-sustaining treatments as indicated on the preceding page, even if my life is at risk.

I understand the decisions that I am making here are in consideration of future circumstances and ask that these be included in my medical records. I understand that this binding Advance Decision remains effective unless I make it clear that my wishes have changed, and that it only comes into effect when I am unable to communicate my wishes by any manner.

Name: _____ Date of birth: ____/____/____

Address: _____

Signature: _____ Date: _____

Distinguishing marks: _____

Signature of a witness to the Advance Decision, who was there when you signed it.

Name of witness: _____

I have witnessed that: _____ has signed this **Advance Decision** in my presence.

(Signature of witness) _____

Relationship of witness: _____ Date: _____

Contact details: _____

Signature of the health care professional with whom I have discussed this Advance Decisions to refuse treatments.

Name of Professional: _____ Job Title: _____

Address: _____

It is my view that (name) _____ has capacity to make this decision at this time. Notes to support this view (or if your views are recorded in this person's medical records, please indicate)

How long have you known this person? _____

Signature of professional: _____ Date: _____

Advance Decision Document (part 5 of 5)

Remember to review this document at regular intervals especially if your circumstances change to ensure it still represents your wishes. Signing and dating at the bottom when you do this will indicate how recently you have thought about it. If you change your mind about anything you have written, tell your GP, hospice nurse, next of kin or appointed representative and amend the document accordingly.

Reviews:

These decisions were reviewed and confirmed by me on:

Signed: _____ Date: ____ / ____ / ____

Signed: _____ Date: ____ / ____ / ____

Signed: _____ Date: ____ / ____ / ____

Signed: _____ Date: ____ / ____ / ____

Putting your affairs in order

Ensuring that your paper work and documents are up to date and easy to find will save time and reduce anxiety for your family/next of kin if you become unable to attend to your affairs or if you are taken ill or suddenly died.

Tick below to show that you have thought about and recorded in a safe place the details listed. Have you nominated someone you can trust who will be able to access those details if the need ever arises?

- _____ Bank Name/Account Details (including credit card)
- _____ Insurance Policies
- _____ Pension Details
- _____ Passport
- _____ Birth/Marriage Certificate
- _____ Mortgage Details
- _____ Hire Purchase Agreements
- _____ Will (see page 18 for further guidance)
- _____ Other Important Documents/Contacts e.g. Solicitor
- _____ Details of any Funeral Arrangements or Preferences
- _____ Addresses and Contact Number of Family, Friends and Colleagues
- _____ Organ Donation / Donor Card
- _____ Tax Office Address and Contact Details
- _____ Other _____
- _____
- _____
- _____
- _____

Making a Will

Many problems occur when a person dies without making a Will as there are clear regulations which dictate how your possessions would be allocated.

If there is no Will the time taken to sort things out can be lengthy and expensive and will cause added stress to your family/next of kin.

In addition, the outcome of this process may not be as you would wish, so it is advisable to make a Will to ensure that your personal effects are left to the people you want to inherit them.

You can make a Will without a solicitor, and forms can be purchased from stationers or via the internet. This is only advisable if the Will is straightforward; the Law Society suggests that specialist advice is sought from a solicitor.

Think about the following aspects prior to visiting a solicitor as this will save you time and money.

- ✓ A list of all beneficiaries (people who you would like to benefit from your Will) - and what you would like them to receive
- ✓ A list of your possessions -savings, pensions, insurance policies, property etc
- ✓ Any arrangements you want for your dependants or pets
- ✓ Decide who will be your executor(s) - the person/s who will deal with distributing your money and possessions after your death. You may have up to four, but it is a good idea to have at least two in case one dies before you do. They can also be beneficiaries and care should be taken when choosing executors to ensure that they are suitable and also willing.

Related documents

1. Preferred Priorities for Care.

This Advance Care Plan document is to complement the Preferred Priorities for Care (PPC) that your health care professional may have completed with you.

If so, then it would be useful to keep these two documents together.

2. Do Not Attempt Cardiopulmonary Resuscitation

If your Advance Care Plan includes a determination to refuse resuscitation, you may wish to discuss completing a Do Not Attempt Cardiopulmonary Resuscitation form (DNACPR) with your doctor.

This document could then be kept with your Advance Care Plan.



Colchester Hospital University 
NHS Foundation Trust

your local healthcare provider

anglian community enterprise



St Helena Hospice
your time...your hospice
Registered Charity Number 280919

Working in partnership with:



Adapted from Gloucester NHS advance care plan Published 2011

Appendix 4

Research participant documentation

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A4.1 E-mail invitation to interview participants

Subject: Research project investigating current practice in advance care planning

Dear Colleague,

Dr Benedict Hayhoe (GP Registrar) and Prof. Amanda Howe (Professor of Primary Care) of UEA invite you to participate in a research project investigating current practice in advance care planning. We are interested in GPs' knowledge and experience of advance care planning and would be very grateful if you could agree to take part in a brief interview on this subject.

Further details on involvement in this research are available in the attached information sheet.

If you feel able to help, please reply as soon as possible to [e-mail address of member of university administrative staff].

Many thanks,

Yours sincerely,

[Name of member of university administrative staff]

A4.2 Interview information sheet

Research Subject information sheet: interview

Title: Advance care planning in primary care in the East of England: a qualitative study.

Sponsor: University of East Anglia. **Study approved by:** Norfolk Research Ethics Committee.

Investigator: Dr Benedict Hayhoe, academic GP Registrar.

You are being asked to take part in a study, developed for educational purposes, that aims to investigate current practice in advance care planning in primary care, seeking to establish what is good practice in this setting.

Your participation will involve being interviewed by Dr Hayhoe, answering questions regarding your knowledge and experience of advance care planning in primary care. The interview will take approximately 30 minutes and will be conducted at your place of work. A single commitment only will be required and you will not be asked to take part in any subsequent parts of the study.

No significant risks to you as a participant are anticipated other than the inconvenience of the time taken to complete the interview. However should you find the discussion distressing, you may terminate the interview at any time and associated data will be destroyed.

Although there may be no immediate gain to you as a result of your participation, it is hoped that the study will result in beneficial advice for primary care clinicians on the application of advance care planning in primary care.

Interviews will be audio recorded. Recordings will subsequently be transcribed and stored in an anonymous form, with the original recording destroyed. No data will be released or published in a way that could be personally identifiable, nor will it be made available to anyone not directly involved in the study.

Your participation is voluntary. If you wish to withdraw from the study you are free to do so at any time. Any information held about you would then be destroyed.

When the study is completed, we will be happy to inform you of the results. If you have any further questions in the meantime please do not hesitate to contact:

Dr Benedict Hayhoe
c/o Med 1 Building,
School of Medicine, Health Policy and Practice,
University of East Anglia, Norwich NR4 7TJ

If you have any concerns about your involvement, please contact the Principal Investigator:

Prof. Amanda Howe
Med 1 Building,
School of Medicine, Health Policy and Practice,
University of East Anglia, Norwich NR4 7TJ Tel. 01603 593929

A4.3 Interview consent form



School of Medicine,
Health Policy and Practice
Institute of Health

University of East Anglia
Norwich NR4 7TJ
Norfolk

Tel: +44 (0) 1603 456161
Direct: +44 (0) 1603 593929
www.uea.ac.uk/med

CONSENT FORM

Project title: Advance care planning in primary care.

Name of Researcher: Dr Benedict Hayhoe.

Participant identification number:

Please initial

1. I confirm that I have read and understood the information sheet (v. 2) for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, and that my legal rights will not be affected. ☐
3. I understand that relevant sections of my data collected during the study may be looked at by individuals from regulatory authorities or from the NHS trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐
4. I understand that the interview will be electronically recorded and that this recording will be transcribed and anonymized. ☐
5. I understand that any information given by me may be used in future reports, articles or presentations by the research team but that my name will not appear in any such reports, articles or presentations. ☐
6. I agree to take part in the above study. ☐

Name of participant. Signed. Date.

Name of researcher. Signed. Date.

A4.4 Interview guide for GPs

Interview guide

What do you understand by the term ‘advance care planning’ (ACP)?

Can you think of any examples of this from your practice?

How much experience do you have of ACP?

Why should we carry out ACP in primary care?

Do you have any ideas as to how we should address ACP in primary care?

Who initiates ACP? And who should?

- Is this different for different elements of ACP?

Do you have any systems for documentation and review of ACP in your practice to ensure that ACP is available and up to date?

Re previous experiences - what was good or worked well about this?
 - did you encounter any problems?

In general, what would you say are the major benefits of ACP?

- For patients? - For healthcare systems or professionals?

What are the main problems with ACP?

Is there anything that would be of assistance to you in doing ACP with patients?

Do you think that there may be inequalities in ACP?

- Do some patients get the advantage of this and others not?

Can you think of any significant ethical problems with ACP?

How would you go about assessing a patient’s capacity to take part in ACP?

Have you read anything recently (press, journals, guidance) about ACP?

There is now RCP and GMC guidance on ACP?

- Do you use these? Have you found them useful in your practice?
- Do you think GPs do this without being aware of guidance or calling it ACP?

If seems to be on the wrong track in terms of definition: ‘Some people use ACP to mean...’

Do you think you do this but haven’t called it ACP?

Based on this definition what would you say to these questions?

If seems well informed:

Do you think your views are shared by your colleagues?

Do you have any personal experience of ACP?

Where did you get your knowledge relating to ACP?

Interview guide for GPs – page 2

Some people use ACP to mean...

A process of decision making that aims to help patients to establish decisions about future care which take effect when they lose capacity.

Usually a series of face to face discussions between patient and doctor.

Seeks to clarify understanding of illness and treatment, as well as beliefs, values and goals of care, before considering wishes for future care.

Three possible outcomes, defined in the MCA 2005:

1. Advance statement of wishes: allows the person to state preferences or wishes for future care, which are later considered when assessing his 'best interests'. This may take the form of a general list of beliefs and values, or describe more specific preferences for treatment.
2. Advance decision to refuse treatment: a legally binding refusal of treatment in advance.
3. Lasting Power of Attorney (LPA) for health and welfare decisions: the appointment of someone to make decisions, subject to 'best interest' criteria, on the patient's behalf when he loses capacity.

A4.5 Interview guide for Psychiatrists

Interview guide: psychiatrists

What do you understand by the term ‘advance care planning’ (ACP)?

Can you think of any examples of this from your practice?

How much experience do you have of ACP?

Who should have ACP?

Who initiates ACP? And who should? And where?

- Is this different for different elements of ACP?

Why should we carry out ACP in primary care?

Do you have any ideas as to how we should address ACP in primary care?

Do you have any systems for documentation and review of ACP to ensure that ACP is available and up to date?

Re previous experiences - what was good or worked well about this?

- did you encounter any problems?

In general, what would you say are the major benefits of ACP?

- For patients? - For healthcare systems or professionals?

What are the main problems with ACP?

Can you think of any significant ethical problems with ACP?

Do you think that there may be inequalities in ACP?

- Do some patients get the advantage of this and others not?

Is there anything that would be of assistance to you in doing ACP with patients?

How would you go about assessing a patient’s capacity to take part in ACP?

Have you read anything recently (press, journals, guidance) about ACP?

There is now RCP and GMC guidance on ACP?

- Do you use these? Have you found them useful in your practice?
- Do you think GPs do this without being aware of guidance or calling it ACP?

If seems to be on the wrong track in terms of definition: ‘Some people use ACP to mean...’

Do you think you do this but haven’t called it ACP?

If seems well informed:

Do you think your views are shared by your colleagues?

Do you have any personal experience of ACP?

Where did you get your knowledge relating to ACP?

Interview guide for Psychiatrists – page 2

Some people use ACP to mean...

A process of decision making that aims to help patients to establish decisions about future care which take effect when they lose capacity.

Usually a series of face to face discussions between patient and doctor.

Seeks to clarify understanding of illness and treatment, as well as beliefs, values and goals of care, before considering wishes for future care.

Three possible outcomes, defined in the MCA 2005:

1. Advance statement of wishes: allows the person to state preferences or wishes for future care, which are later considered when assessing his 'best interests'. This may take the form of a general list of beliefs and values, or describe more specific preferences for treatment.
2. Advance decision to refuse treatment: a legally binding refusal of treatment in advance.
3. Lasting Power of Attorney (LPA) for health and welfare decisions: the appointment of someone to make decisions, subject to 'best interest' criteria, on the patient's behalf when he loses capacity.

A4.6 E-mail invitation to focus group participants

Subject: Advance care planning research project

Dr Benedict Hayhoe (GP Registrar) and Prof. Amanda Howe (Professor of Primary Care) of University of East Anglia invite you to participate in a research project investigating current practice in advance care planning.

We are interested in peoples' views, understanding and experience of advance care planning and would be very grateful if you could agree to take part in a focus group on this subject. No special knowledge or experience is needed. We have already interviewed a number of GPs about advance care planning, and feel that we would gain a much greater understanding of this important area with the views of lay people and carers.

We hope to set up focus groups within the next month, and expect them to last about 45 minutes.

Further details on involvement in this research are available in the attached information sheet.

If you feel able to help, please reply as soon as possible to [e-mail address]

Many thanks,
Yours sincerely,

Benedict Hayhoe
Academic GP Registrar

A4.7 Focus group pre session letter

Address:

Telephone:

E-mail:

14th September 2011

Dear

Thank you so much for agreeing to take part in a focus group session for our research study on advance care planning in primary care.

I am writing to confirm that this session will take place as planned on **Tuesday 20th September at the University of East Anglia**. The meeting will be in **room 1.11 in the MED building, starting at 3pm**, and I expect it to finish by 5pm. I will lead the session, with the support of my colleague and supervisor Professor Amanda Howe, and there will be five other participants as well as you.

Parking is available on site in the main car park, and permits are available for the afternoon from the UEA security lodge. The car park is labelled **P1** on the enclosed map and the security lodge **C17**. The MED building, where the meeting will be held, is marked **H2**.

I have already interviewed a number of GPs on the subject of advance care planning, and the purpose of this focus group is to discuss and expand on some of the findings of these interviews. Prior to the group meeting, I thought it might be helpful for you to see a short list of some of the kinds of questions which we have discussed with GPs (enclosed). When we meet, we can then talk about your own feelings about these as well as what some of the GPs thought.

You should previously have seen the enclosed information sheet and consent form. We will complete and collect consent forms at the beginning of the session so it would be helpful if you could bring these with you. The information sheet and consent forms will also form the basis of the ground rules for the session, which we will discuss before we start.

Some members of the group advised us on a summary of the project while we were developing our ideas. I therefore enclose this just for your information; we will not be discussing this during the group session.

Finally we are very happy to pay your travel expenses in attending this meeting. In order to save time, I will send you each a claim form to complete after the session.

Focus group pre session letter – page 2

I hope that this is all acceptable to you. Prof. Howe and I are very much looking forward to meeting you and hope that you will enjoy the session. If you have any queries prior to Tuesday do please do not hesitate to contact me either by telephone or e-mail.

Many thanks again for agreeing to take part.

Yours sincerely,

A handwritten signature in black ink, reading 'B Hayhoe', enclosed within a thin black rectangular border.

Dr Benedict Hayhoe

A4.8 Focus group information sheet

Research Subject information sheet: focus group

Title: Advance care planning in primary care in the East of England: a qualitative study.

Sponsor: University of East Anglia. **Study approved by:** Norfolk Research Ethics Committee.

Investigator: Dr Benedict Hayhoe, academic GP Registrar.

You are being asked to take part in a study, developed for educational purposes, that aims to investigate current practice in advance care planning in primary care, seeking to establish what is good practice in this setting.

Your participation will involve taking part in a focus group, led by Dr Hayhoe, discussing your views on and experience of advance care planning in primary care. The session will take approximately 45 minutes. A single commitment only will be required and you will not be asked to take part in any subsequent parts of the study.

No significant risks to you as a participant are anticipated other than the inconvenience of the time taken to attend the focus group. However should you find the discussion distressing, you may withdraw from the group at any time and associated data will be destroyed.

Although there may be no immediate gain to you as a result of your participation, it is hoped that the study will result in beneficial advice for primary care clinicians on the application of advance care planning in primary care.

Focus groups will be audio recorded. Recordings will subsequently be transcribed and stored in an anonymous form, with the original recording destroyed. No data will be released or published in a way that could be personally identifiable, nor will it be made available to anyone not directly involved in the study.

Your participation is voluntary. If you wish to withdraw from the study you are free to do so at any time. Any information held about you would then be destroyed.

When the study is completed, we will be happy to inform you of the results. If you have any further questions in the meantime please do not hesitate to contact:

Dr Benedict Hayhoe
c/o Med 1 Building,
School of Medicine, Health Policy and Practice,
University of East Anglia, Norwich NR4 7TJ

If you have any concerns about your involvement, please contact the Principal Investigator:

Prof. Amanda Howe
Med 1 Building,
School of Medicine, Health Policy and Practice,
University of East Anglia, Norwich NR4 7TJ Tel. 01603 593929

A4.9 Focus group consent form



School of Medicine,
Health Policy and Practice
Institute of Health

University of East Anglia
Norwich NR4 7TJ
Norfolk

Tel: +44 (0) 1603 456161
Direct: +44 (0) 1603 593929
www.uea.ac.uk/med

CONSENT FORM

Project title: Advance care planning in primary care.

Name of Researcher: Dr Benedict Hayhoe.

Participant identification number:

Please initial

1. I confirm that I have read and understood the information sheet (v. 2) for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, and that my legal rights will not be affected. ☐
3. I understand that relevant sections of my data collected during the study may be looked at by individuals from regulatory authorities or from the NHS trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐
4. I understand that the focus group will be electronically recorded and that this recording will be transcribed and anonymized. ☐
5. I understand that any information given by me may be used in future reports, articles or presentations by the research team but that my name will not appear in any such reports, articles or presentations. ☐
6. I agree to take part in the above study. ☐

Name of participant. Signed. Date.

Name of researcher. Signed. Date.

A4.10 Focus group pre session questions

Some questions asked of GPs

What do you understand by the term 'advance care planning' (ACP)?

Have you come across any examples of ACP?

Why should we carry out ACP / what sort of people may find it useful?

Who should suggest / start ACP with people?

Where, when and how should it be done?

What would you say are the major benefits of ACP?

What are the main problems with ACP?

What could be done to improve ACP in primary care?

A4.11 Focus group ground rules

Focus group ground rules

We hope that this session will be interesting and enjoyable for all of us taking part. To help it run smoothly, we would like all participants to be aware of the following:

- Participation is entirely voluntary
- All discussions within the group are confidential
- We will use first names only during the session
- Only one person will talk at a time
- We will respect each other's contributions and listen when they are speaking
- We will aim for equal participation from everyone
- It is important for us to hear everyone's ideas and opinions; there are no right or wrong answers
- We would like to hear all sides of each issue, both positive and negative
- In order to cover as much as possible we will have to stay focused, and may have to move the discussion on from time to time
- Mobile phones!

A4.12 Focus group guide

Focus group guide with prompts from GP responses

What do you understand by the term ‘advance care planning’ (ACP)?

GPs seemed unfamiliar with the term, though often had some understanding of the concepts involved.

Have you read / heard / seen anything recently (press, radio, TV) about ACP?

Have you come across any examples of ACP?

Most GPs had little experience, though some had experience of powers of attorney.

Why should we carry out ACP / what sort of people may find it useful?

End of life / palliative care, dementia, heart failure, motor neurone disease, cancer, stroke, chronic kidney disease, COPD, chronic / life limiting illnesses.

Where should we carry out ACP?

Primary care / memory clinic / home visit

Who should suggest / initiate ACP?

GP / solicitor / psychiatrist / nurse

How should we go about it? What would you expect from your GP?

And from other professionals?

Should family / carers be involved?

Some GPs felt it was important to discuss with family and keep them informed – they are most able to ensure that patients’ wishes are followed

How should ACP be kept / recorded?

Recorded in notes / electronic record. Various ideas re making ACP known / available – documentation with OOH and ambulance / Medic Alert bracelets / ACP file at home / milk bottle message etc.

If previous experiences / examples - what was good or worked well about this?

- what was not so good about it?

In general, what would you say are the major benefits of ACP?

- For patients?

Feeling of control, opportunity to voice concerns / opinions, more open, feel more involved in care, dignity, autonomy, avoid unwanted interventions, able to make your own choices about the future, comfort, views respected.

Focus group guide – page 2

- For families and carers?

Clear on what is happening, reduced stress, less disputes, takes away burden of decisions, supports family when stopping treatments.

- For healthcare systems or professionals?

Understanding of what patient wants, know when not to treat, feel doing the right thing, clear plan, easier decisions, reduced responsibility, easier with family.

What are the main problems with ACP?

May change your mind, medical advances, professionals / family may not want to follow it, fear of misuse / coercion, not in the right place at the right time, only an ideal scenario – difficult to follow, difficult to do – uncomfortable to discuss / too much time / specific or general.

Are there any ethical problems?

Change of mind, difficult to predict future wishes, coercion, financial incentives - saving healthcare costs.

Do you think there is a problem of some patients getting the advantage of this and others not?

Middle class, intelligent, well educated, own GP / healthcare professional 'gets on with patient' / finds them easy to talk to.

Too expensive for some, just don't know about it – publicity / discussion about ACP in certain area / groups only, patients who do not attend for healthcare will not get ACP either


What could be done to improve ACP in primary care?

Training, guidance, support from other professionals, publicity.

Any other suggestions / comments

Thank you!

A4.13 Newsletter advertisement for questionnaire survey



Newsletter

Issue 76 June 2012

Inside this Issue:


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Courses at a glance July/August

July 3rd	Family Planning Study Day for HCAs
4th	Telephone Consulting for Nurses
10th	Cardiovascular Conference
10th	Mid Essex Evening Meeting
11th	Medical Terminology
12th	New Clarity Appraisal Toolkit Training—Colchester
12th	New Clarity Appraisal Toolkit Training—Basildon
17th	Mid Essex Evening Meeting
18th	Insulin Initialisation
19th	QOF Changes & How to Cope with Them
26th	Immunisation/Vaccination Update for HCAs
16th August	Colchester PGMC Evening Meeting

For further courses check out the 'Course List' on our website
www.essexequip.nhs.uk

Mid Essex GPs & Nurse Practitioners
Masterclass—Early Diagnosis of Cancer
Thursday 13th September 2012
1.15pm—4.45pm
Ivy Hill Hotel, Margareting



Diabetes Conference 18th October 2012
Hylands House, Chelmsford

The flyer has been emailed to all GPs & Nurses in Essex
[click here to view](#)

Cardiovascular Conference 10th July, Colchester Stadium

There are still a few places left but it is filling fast !!

This conference is free but a £50 booking deposit is required to secure a place

Advance Care Planning Research Study

Advance care planning (ACP) is a process which enables patients to consider and make known their preferences about healthcare for the future. This may include refusal of particular treatments, details of preferred kinds of care, or appointment of someone to act as a proxy decision maker and can then be taken into account if they are later unable to make decisions for themselves.

Dr Benedict Hayhoe (General Practitioner) and Prof. Amanda Howe (Professor of Primary Care) of University of East Anglia, are carrying out a study investigating current practice in ACP in primary care, and are very interested in your views on this process.

Supported by EQUIP, they will be inviting a selection of GPs, GP Registrars, Practice Nurses and Practice Managers to complete a brief (10-15 minutes) questionnaire on ACP, they would be very grateful for your support in completing this.

If you are interested and would like more information on this study, or would like to be sent a questionnaire, please contact

Respiratory Conference—14th June 2012.

88 delegates attended the Respiratory Conference at Hylands House. The plenary sessions and workshops were well evaluated. Some hand outs were too small to read and these can be found on the EQUIP website. If you would like any other hand outs please email shirley.gair@nhs.net

A4.14 E-mail invitation to questionnaire survey participants

Dear Colleagues,

Advance care planning in primary care in the East of England

Advance care planning (ACP) is a process enabling patients to make known their preferences about healthcare for the future, to be taken into account should they lose the ability to make decisions for themselves. This may include refusal of particular treatments, details of preferred kinds of care, or appointment of someone to act as a proxy decision maker.

In this unfunded project, carried out as part of an MD studentship, we are investigating current practice in ACP in primary care, and are very interested in your views on this process.

As part of our study we are inviting a selection of GPs, GP Registrars, Practice Nurses and Practice Managers to participate in a brief (10-15 minutes) questionnaire survey on ACP, and would be very grateful for your support in completing a questionnaire.

Thank you for taking the time to read this message. We would very much appreciate it if you could look out for our questionnaire in your post over the next few weeks and complete and return if possible.

If you have any questions about the survey, or would like to ensure that you receive copies of the questionnaire, please do not hesitate to contact us by e-mail: [e-mail address]

May we take this opportunity to wish all at your practice a very happy New Year!

A copy of the study information sheet is attached.

Yours sincerely,

Dr Benedict Hayhoe and Prof. Amanda Howe
University of East Anglia

A4.15 Questionnaire survey information sheet

Research subject information sheet: questionnaire

Title: Advance care planning in primary care in the East of England: a qualitative study.

Sponsor: University of East Anglia. **Study approved by:** Norfolk Research Ethics Committee.

Investigator: Dr Benedict Hayhoe, General Practitioner.

You are being asked to take part in a study, developed for educational purposes, that aims to investigate current practice in advance care planning in primary care, seeking to establish what is good practice in this setting.

Your participation will involve completing the following brief questionnaire, answering questions regarding your knowledge and experience of advance care planning in primary care. The questionnaire should take 10 to 15 minutes to complete. A single commitment only will be required and you will not be asked to take part in any subsequent parts of the study.

No significant risks to you as a participant are anticipated other than the inconvenience of the time taken to complete the questionnaire. However should you find the content distressing, you may terminate the questionnaire at any time and associated data will not be recorded.

Although there may be no immediate gain to you as a result of your participation, it is hoped that the study will result in beneficial advice for primary care clinicians on the application of advance care planning in primary care.

Data from questionnaires will be stored in an anonymous form. No data will be released or published in a way that could be personally identifiable, nor will it be made available to anyone not directly involved in the study.

Your participation is voluntary. If you wish to withdraw from the study you are free to do so at any time. Any information held about you would then be destroyed.

When the study is completed, we will be happy to inform you of the results. If you have any further questions in the meantime please do not hesitate to contact:

Dr Benedict Hayhoe
c/o Med 1 Building,
School of Medicine, Health Policy and Practice,
University of East Anglia, Norwich NR4 7TJ

If you have any concerns about your involvement, please contact the Principal Investigator:

Prof Amanda Howe
Med 1 Building,
School of Medicine, Health Policy and Practice,
University of East Anglia, Norwich NR4 7TJ Tel. 01603 593929

Your completion and submission of the following questionnaire represents your consent to take part in this study.

Questionnaire info / consent sheet v3 4.4.12

A4.16 Questionnaire for clinical staff

Questionnaire: Clinical Staff**Advance Care Planning in Primary Care**

Thank you very much for agreeing to take part in this survey.

Please read the following information before completing the questionnaire.

What is advance care planning (ACP)?

ACP is a process which enables patients to consider and make known their preferences about healthcare for the future. This may include various elements such as refusal of particular treatments, details of preferred kinds of care, or appointment of someone to act as a proxy decision maker.

What are advance care plans (ACPs) for?

Some people worry about how they would be treated if they became unable to express their own wishes. ACPs provide information about future wishes, which health professionals can take into account should patients subsequently lose the capacity to make decisions for themselves.

Why are we investigating ACP?

Although increasingly promoted in the UK there seems to be little UK primary care research on ACP. We are interested in the views of primary care professionals on ACP and we hope that your answers will help us gain a detailed picture of current professional opinion and understanding of ACP, essential to identifying any needs for development.

Terms used in ACP

Various terms have been used to describe elements of ACP. We include the following as representing ACP or related concepts for the purposes of this survey:
Advance decisions, advance directives, advance statements, Lasting (or Enduring) Powers of Attorney (LPA / EPA), living wills, values statements, preferred place of care (PPC).

The process of ACP

We have already learned that practitioners carry out ACP over a period of time rather than as a single event. We are also aware that all patients will need a personalised approach to ACP.

Before starting the questionnaire please select your professional role:

GP	<input type="checkbox"/>	Practice nurse	<input type="checkbox"/>
GP Registrar	<input type="checkbox"/>	Practice manager	<input type="checkbox"/>
		Other	

Please do not complete this questionnaire if you have already participated in an interview on advance care planning with the study investigator, Dr Benedict Hayhoe.

There are separate questionnaires for practice managers and clinical staff.

Questionnaire for clinical staff – page 2

Advance Care Planning (ACP) in Primary Care**Clinical Staff**

Please answer the following questions if you are a clinician (GP, GP Registrar, Practice Nurse etc.)

1. What is your experience of ACP? (Please select a number to indicate your agreement with each statement)

	Strongly agree			Strongly disagree	
I am familiar with the concept of ACP (as described on the previous page)	1	2	3	4	5
I have encountered patients with ACPs in primary care	1	2	3	4	5
I have been involved in helping patients make ACPs	1	2	3	4	5

2. What are your feelings about helping patients make ACPs? (Please select a number to indicate your agreement with each statement)

	Strongly agree			Strongly disagree	
Generally patients are happy to be asked about ACP	1	2	3	4	5
I am in favour of the concept of ACP	1	2	3	4	5
It is important to offer patients ACP in primary care	1	2	3	4	5
GPs should be involved in ACP (their role is important)	1	2	3	4	5
I would want to be involved in this process (time and expertise permitting)	1	2	3	4	5
We should do more ACP in primary care	1	2	3	4	5
I feel confident in helping patients make ACPs	1	2	3	4	5
I feel confident in assessing patients' mental capacity to participate in ACP	1	2	3	4	5
I am familiar with professional guidance on ACP	1	2	3	4	5
I am confident in my understanding of legislation governing the use of ACP	1	2	3	4	5

Questionnaire for clinical staff – page 3



3. What do you feel are the important benefits of ACP? (Please select a number to indicate your agreement with each statement)

	Strongly agree			Strongly disagree	
Helps communication (clinicians / patients / relatives / carers)	1	2	3	4	5
Reduces stress / anxiety in patients	1	2	3	4	5
Reduces stress / anxiety in relatives / carers	1	2	3	4	5
Gives patients control over their future care	1	2	3	4	5
Makes decision making easier for clinicians	1	2	3	4	5
Makes decision making easier for relatives / carers	1	2	3	4	5
Reduces inappropriate investigations / treatments	1	2	3	4	5
Reduces inappropriate hospital admissions	1	2	3	4	5
Saves healthcare costs	1	2	3	4	5
Other benefits (please specify)					

4. In what specific medical conditions or situations do you feel ACP might be useful? (Please tick to indicate your agreement, and list as many others as you wish)

Cancer	<input type="checkbox"/>	Frailty	<input type="checkbox"/>	Stroke	<input type="checkbox"/>
Dementia	<input type="checkbox"/>	Heart failure	<input type="checkbox"/>	Terminal illness	<input type="checkbox"/>
Other(s).....					
.....					
.....					

5. What do you feel is generally the best time to carry out ACP with patients in primary care? (Please select a number to indicate your agreement with each statement)

	Strongly agree			Strongly disagree	
As early as possible	1	2	3	4	5
Around the time of a new (significant) diagnosis	1	2	3	4	5
At a time of relative wellness	1	2	3	4	5
Routinely, above a certain age threshold	1	2	3	4	5
Routinely, in certain medical conditions (e.g. those you listed in question 4)	1	2	3	4	5
At other times (please specify)					

Questionnaire for clinical staff – page 4



6. What do you feel are the important practical and ethical problems with ACP?
(Please select a number to indicate your agreement with each statement)

	Strongly agree			Strongly disagree	
ACPs may be difficult to interpret	1	2	3	4	5
ACPs may be difficult to apply in practice	1	2	3	4	5
ACPs may conflict with clinical opinion	1	2	3	4	5
It is difficult to find the right time for ACP	1	2	3	4	5
If left too late, patients may lack capacity to do ACP	1	2	3	4	5
May not be available in the right place at the right time	1	2	3	4	5
It is difficult to predict future wishes for ACP	1	2	3	4	5
Patients may change their mind after making an ACP	1	2	3	4	5
Patients may be coerced into making decisions	1	2	3	4	5
ACP might be used to save the NHS money	1	2	3	4	5
Other problems with ACP (please specify)					

7. What do you feel are the important barriers to making ACPs? (Please select a number to indicate your agreement with each statement)

	Strongly agree			Strongly disagree	
ACP is not equally available to all patients	1	2	3	4	5
Clinicians are uncomfortable with discussing ACP	1	2	3	4	5
People don't know about ACP	1	2	3	4	5
ACP takes up too much time	1	2	3	4	5
ACP is too expensive	1	2	3	4	5
Other barriers (please specify)					

8. Would you like to have an ACP for yourself? (Please select a number or tick as appropriate)

	Strongly agree			Strongly disagree	
I would like to have my own ACP	1	2	3	4	5
I am likely to make my own ACP in the next year	1	2	3	4	5
I would advise close family members to make ACPs	1	2	3	4	5
I have already made my own ACP	Yes <input type="checkbox"/>		No <input type="checkbox"/>		

Questionnaire for clinical staff – page 5



9. How do you think we might best improve use of ACP in primary care? (Please select a number to indicate your agreement with each statement)

	Strongly agree			Strongly disagree	
Involve other healthcare professionals in providing ACP	1	2	3	4	5
More training for clinicians in ACP	1	2	3	4	5
More publicity on ACP	1	2	3	4	5
Make ACP a routine part of care	1	2	3	4	5
Make available a brief pro-forma for ACP	1	2	3	4	5
Other ideas for improvement (please specify)					

10. Do you have any other comments or thoughts on ACP in primary care which you would like to draw to our attention?

.....

.....

.....

.....

Finally, please complete the following demographic information:

Age

Sex Male ☐ Female ☐

How many years have you worked in your current role?

Many thanks for taking the time to complete this questionnaire.

If you would like to find out more about ACP, the following web resources may be of interest:

http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_advanced_care_planning.asp

<http://www.rcplondon.ac.uk/resources/concise-guidelines-advance-care-planning>

<http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide>

A4.17 Questionnaire for Practice Managers

Questionnaire: Practice Managers

Advance Care Planning in Primary Care



Thank you very much for agreeing to take part in this survey.

Please read the following information before completing the questionnaire.

What is advance care planning (ACP)?

ACP is a process which enables patients to consider and make known their preferences about healthcare for the future. This may include various elements such as refusal of particular treatments, details of preferred kinds of care, or appointment of someone to act as a proxy decision maker.

What is ACP for?

Some people worry about how they would be treated if they became unable to express their own wishes. ACPs provide information about future wishes, which health professionals can take into account should patients subsequently lose the capacity to make decisions for themselves.

Why are we investigating ACP?

Although increasingly promoted in the UK there seems to be little UK primary care research on ACP. We are interested in the views of primary care professionals on ACP and we hope that your answers will help us gain a detailed picture of current professional opinion and understanding of ACP, essential to identifying any needs for development.

Terms used in ACP

Various terms have been used to describe elements of ACP. We include the following as representing ACP or related concepts for the purposes of this survey:
Advance decisions, advance directives, advance statements, Lasting (or Enduring) Powers of Attorney (LPA / EPA), living wills, values statements, preferred place of care (PPC).

The process of ACP

We have already learned that practitioners carry out ACP over a period of time rather than as a single event. We are also aware that all patients will need a personalised approach to ACP.

Before starting the questionnaire please select your professional role:

GP	<input type="checkbox"/>	Practice nurse	<input type="checkbox"/>
GP Registrar	<input type="checkbox"/>	Practice manager	<input type="checkbox"/>
		Other	

Please do not complete this questionnaire if you have already participated in an interview on advance care planning with the study investigator, Dr Benedict Hayhoe.

There are separate questionnaires for practice managers and clinical staff.

Questionnaire for Practice Managers – page 2

Advance Care Planning (ACP) in Primary Care Practice Managers



Please answer the following questions if you are a practice manager.

1. How many patients do you have registered at your practice?

2. Are you familiar with the concept of ACP (as we have described it)? Yes ☐ No ☐

3. Does your practice have a system for recording when patients have an advance care plan (ACP)? Yes ☐ No ☐
Don't know ☐

3a. If yes, please specify

.....

4. Does your practice have any process for review of ACPs? Yes ☐ No ☐
Don't know ☐

If yes,

4a. How often are ACPs reviewed?

4b. What process is used?

.....

5. Please could you estimate the number of patients with ACPs in your practice? If possible, please run a computer search. (Suggested Read codes are at end of questionnaire)

.....

(If this is not possible, please leave blank. We may be able to visit some practices subsequently to carry out searches.)

6. Do your clinical staff have access to any ACP documents to assist with carrying out ACP? Yes ☐ No ☐
Don't know ☐

7. Does your practice have any information leaflets or posters to inform patients about ACP? Yes ☐ No ☐
Don't know ☐

Questionnaire for Practice Managers – page 3



8. Do you have any other comments or thoughts on ACP in primary care which you would like to draw to our attention?

.....

.....

.....

Many thanks for taking the time to complete this questionnaire.

If you would like to find out more about ACP, the following web resources may be of interest:

http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_advanced_care_planning.asp

<http://www.rcplondon.ac.uk/resources/concise-guidelines-advance-care-planning>

<http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide>

Suggested Read codes for question 5. (Please include hierarchical Read code 'children')

Please include advance directives, advance decisions, advance or values statements, powers of attorney, living wills, and preferred place of care.

If you are aware of or use other codes, please record these here.....

Term	CTV3 (SystmOne)	Version2 (All other clinical systems)
Preferred place of death	XalpX%	94Z..%
Preferred place of care	XaQTP%	8Ce..%
Has made a living will	XaCEN	13VH.
Power of attorney	9W...%	9W...%
Power of attorney proceedings	Ua01b	
Power of attorney medical report	9W1..	9W1..
Has end of life advance care plan	XaRFF	8CME.
Advanced directive administration	XaCEJ	9X...%
Advance directive status	XaCEK%	
Not for resuscitation	Xa9tT	1R1..
Does not wish to receive blood products	XaWON	9Ng8.
[V]Refusal of treatment for reasons of religion or conscience	ZV626	ZV626

* % including sub codes

Appendix 5

Participant demographic data

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A5.1 Interview participant demographic data

Participant	Personal details			Special interests / additional qualifications	Practice details			Population profile			
	Age	Sex	Years as GP		Number of GPs	List size	Teaching / training	Young / old	Socioeconomic spread	Rural / urban	Nursing homes
IN-1	32	F	2	Med student teaching (studying for MClinEd), Women's Health (DRCOG),	3 FTE partners	6300	Yes	Average	Average	Urban	Yes (3), incl. dementia
IN-2	45	F	20	MSc Primary Care, MRCPsych, Mental Health, Trainee + undergrad teaching	9 partners, 2 salaried	14000	Yes	Old, 30% over 85 in branch practice	Middle / upper with some rural deprivation	Rural	Yes (4)
IN-3	55	M	26	Acupuncture, Psychiatry	8	13000	Yes	Young adult		Urban	Yes (3)
IS-4	38	M	8.5	DRCOG	6	10000	No	Young	Fluid population	Semi urban	Several
IN-5	38	F	6	Palliative Care, teaching	5	7800	Yes	Average	Average	Average	
IN-6	31	F	18	Women's / Sexual Health, DRCOG, DFSRH	5	7000	No	Young	Deprived	Urban	No
IS-7	63	M	35	Teaching (Professor at Medical School), FRCGP, FRCP	8	10500	Yes	Mixed	Mixed	Semi rural	Yes (1)
IN-8	53	F	20	DO, MRCGP, DCH	5	10000	Yes	Mixed		Urban	
IN-9	50	F	8	Microbiology, Theology, teaching	9	10000	Yes	Mixed	Mixed	Urban	Yes (1)
ISWE-10	30	M	3	PGDip (Cardiology), DFSRH, DRCOG	7	11500	Yes	Mixed	Middle class	Sub-urban	Yes

Interview participant demographic data - page 2

Participant	Personal details			Special interests / additional qualifications	Practice details			Population profile			
	Age	Sex	Years as GP		Number of GPs	List size	Teaching / training	Young / old	Socioeconomic spread	Rural / urban	Nursing homes
ISWE-11	36	M	7.5	DRCOG, DFRH	7	14000	No	Elderly	Middle class	Urban	Yes (2)
INEE-12	41	F	6	Pain control, Paediatrics, Obstetrics and Gynae, DFFP, DRCOG	4	8200	Yes	Mixed	Mixed	Urban	No
INEE-13	55	F	25	Paediatrics, education, MRCP (Paeds), PGCert Med Ed, DRCOG	9	14000	Yes	Mixed	Mixed	Mixed	No
INEE-14	54	F	24	Education, BSc Psychology, MSc Med Education	3	6200	Yes	Average	Only 2 small areas of deprivation	Rural	Yes (2)
INEE-15	57	M	21	MSc Clin. Education, GP training	4	6000	Yes	Old		Urban	Yes (2)
ISMH-16	48	M	10	Outcomes, Dementia (Psy)							
ISMH-17	51	F	15	None (Psy)							
ISMH-18	54	F	13	(Psy)							
ISMH-19	52	F	14	Liaison Psychiatry (Psy)							

A5.2 Focus group participant demographic data

Participant 1. Age 64. Sex: female

Previous occupation: Educational Consultant / Advisor

Relevant interests: Trustee for Age UK Norfolk, volunteer for Advice Line (Age UK Norfolk), member Norfolk Older People's Strategic Partnership Board.

Participant 2. Age 74. Sex: female

Previous occupation – Nursing Sister – hospital and community (nursing home)

Relevant interests – Community care.

Participant 3. Age 62. Sex: female

Previous occupation: Sociologist / Social Researcher

Relevant interests: Wrote report for Norfolk County Council on 'How we manage Death and Dying in Norfolk'. Specialist palliative care services.

Participant 4. Age 79. Sex: female

Previous occupation: WRNS. Ministry of Agriculture – milk testing.

Participant 5. Age 67. Sex: female

Occupation: Admin / Advice for Norfolk County Council Education Department.

Previously Head of Marketing Department for Professional Services.

Relevant interests: Advisory Committee, Partnerships for Older People Projects (Norfolk County Council). On interview team for Norfolk County Council Adult Social Services Domiciliary Care. Member of Norfolk Older Persons Forum Committee.

Participant 6. Age 67. Sex: female

Previous occupation: Care Home Manager

Relevant interests: 18 years working in care. Member of Norfolk Older Persons Forum.

A5.3 Questionnaire survey participant demographic data

	Number of respondents	Per cent
<hr/> Professional role		
Practice Manager	37	29.3
Clinicians	89	70.6
GP	73	82.0
GP Registrar	1	1.1
Practice Nurse	14	15.7
Other (community matron)	1	1.1
<hr/>		
Participant characteristics (clinicians only)		
Age		
Less than 40 years	20	23.8
41 – 50	23	27.4
51 – 60	39	46.4
61 – 70	2	2.4
Missing values	5	
Sex		
Male	34	38.6
Female	54	61.4
Missing values	1	
Years in current role		
Less than 10 years	28	36.4
11 – 20	20	26.0
21 – 30	28	36.4
31 – 40	1	1.3
Missing values	12	
<hr/>		

Appendix 6

Questionnaire survey data

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A6.1 Questionnaire for clinical staff: quantitative data and analysisⁱA6.1.1 Question 1: *'What is your experience of ACP?'*ⁱⁱ

Question 1.1. I am familiar with the concept of ACP (as described on the previous page).

	Frequency	Per cent
1 = Strongly agree	26	29.5
2	34	38.6
3	22	25.0
4	5	5.7
5 = Strongly disagree	1	1.1
Total	88*	100.0
Median score = 2		*1 missing value

Question 1.2. I have encountered patients with ACPs in primary care.

	Frequency	Per cent
1 = Frequently	12	13.6
2	27	30.7
3	27	30.7
4	16	18.2
5 = Never	6	6.8
Total	88*	100.0
Median score = 3		*1 missing value

Question 1.3. I have been involved in helping patients make ACPs.

	Frequency	Per cent
1 = Frequently	12	13.6
2	21	23.9
3	21	23.9
4	16	18.2
5 = Never	18	20.5
Total	88*	100.0
Median score = 3		*1 missing value

ⁱ For copies of the questionnaires with which these data were obtained, please see Appendix 4, sections 4.19 and 4.19.

ⁱⁱ Please note as a result of rounding, percentages expressed in these tables will not necessarily sum to exactly 100.

A6.1.2 Question 2: *'What are your feelings about helping patients make ACPs?'***Question 2.1.** Generally patients are happy to be asked about ACP.

	Frequency	Per cent
1 = Strongly agree	8	9.1
2	31	35.2
3	44	50.0
4	5	5.7
5 = Strongly disagree	0	0
Total	88*	100.0
Median score = 3		*1 missing value

Question 2.2. I am in favour of the concept of ACP.

	Frequency	Per cent
1= Strongly agree	36	41.4
2	41	47.1
3	9	10.3
4	1	1.1
5 = Strongly disagree	0	0
Total	87	100.0
Median score = 2		*2 missing values

Question 2.3. It is important to offer patients ACP in primary care.

	Frequency	Per cent
1 = Strongly agree	30	33.7
2	32	36.0
3	25	28.1
4	2	2.2
5 = Strongly disagree	0	0
Total	89	100.0
Median score = 2		

Question 2.4. GPs should be involved in ACP (their role is important).

	Frequency	Per cent
1 = Strongly agree	26	29.2
2	36	40.4
3	23	25.8
4	4	4.5
5 = Strongly disagree	0	0
Total	89	100.0

Median score = 2

Question 2.5. I would want to be involved in this process (time and expertise permitting).

	Frequency	Per cent
1 = Strongly agree	21	23.6
2	35	39.3
3	24	27.0
4	5	5.6
5 = Strongly disagree	4	4.5
Total	89	100.0

Median score = 2

Question 2.6. We should do more ACP in primary care.

	Frequency	Per cent
1 = Strongly agree	27	30.3
2	29	32.6
3	25	28.1
4	7	7.9
5 = Strongly disagree	1	1.1
Total	89	100.0

Median score = 2

Question 2.7. I feel confident in helping patients make ACPs.

	Frequency	Per cent
1 = Strongly agree	12	13.5
2	24	27.0
3	30	33.7
4	18	20.2
5 = Strongly disagree	5	5.6
Total	89	100.0

Median score = 3

Question 2.8. I feel confident in assessing patients' mental capacity to participate in ACP.

	Frequency	Per cent
1 = Strongly agree	18	20.2
2	24	27.0
3	28	31.5
4	14	15.7
5 = Strongly disagree	5	5.6
Total	89	100.0

Median score = 3

Question 2.9. I am familiar with professional guidance on ACP.

	Frequency	Per cent
1 = Strongly agree	6	6.8
2	22	25.0
3	22	25.0
4	27	30.7
5 = Strongly disagree	11	12.5
Total	88*	100.0

Median score = 3

*1 missing value

Question 2.10. I am confident in my understanding of legislation governing the use of ACP.

	Frequency	Per cent
1 = Strongly agree	4	4.5
2	14	15.9
3	26	29.5
4	31	35.2
5 = Strongly disagree	13	14.8
Total	88*	100.0

Median score = 3.5

*1 missing value

A6.1.3 Question 3: *'What do you feel are the important benefits of ACP?'*

Question 3.1. Helps communication (clinicians / patients / relatives / carers).

	Frequency	Per cent
1 = Strongly agree	35	39.3
2	42	47.2
3	10	11.2
4	1	1.1
5 = Strongly disagree	1	1.1
Total	89	100.0

Median score = 2

Question 3.2. Reduces stress / anxiety in patients.

	Frequency	Per cent
1 = Strongly agree	19	21.3
2	46	51.7
3	20	22.5
4	3	3.4
5 = Strongly disagree	1	1.1
Total	89	100.0

Median score = 2

Question 3.3. Reduces stress / anxiety in relatives / carers.

	Frequency	Per cent
1 = Strongly agree	21	23.6
2	45	50.6
3	20	22.5
4	3	3.4
5 = Strongly disagree	0	0
Total	89	100.0

Median score = 2

Question 3.4. Gives patients control over their future care.

	Frequency	Per cent
1 = Strongly agree	34	38.2
2	44	49.4
3	10	11.2
4	1	1.1
5 = Strongly disagree	0	0
Total	89	100.0

Median score = 2

Question 3.5. Makes decision making easier for clinicians.

	Frequency	Per cent
1 = Strongly agree	27	30.3
2	43	48.3
3	15	16.9
4	4	4.5
5 = Strongly disagree	0	0
Total	89	100.0

Median score = 2

Question 3.6. Makes decision making easier for relatives / carers.

	Frequency	Per cent
1 = Strongly agree	22	24.7
2	50	56.2
3	14	15.7
4	3	3.4
5 = Strongly disagree	0	0
Total	89	100.0

Median score = 2

Question 3.7. Reduces inappropriate investigations / treatments.

	Frequency	Per cent
1 = Strongly agree	31	34.8
2	38	42.7
3	14	15.7
4	4	4.5
5 = Strongly disagree	2	2.2
Total	89	100.0

Median score = 2

Question 3.8. Reduces inappropriate hospital admissions.

	Frequency	Per cent
1 = Strongly agree	31	34.8
2	35	39.3
3	18	20.2
4	5	5.6
5 = Strongly disagree	0	0
Total	89	100.0

Median score = 2

Question 3.9. Saves healthcare costs.

	Frequency	Per cent
1 = Strongly agree	13	14.6
2	21	23.6
3	36	40.4
4	15	16.9
5 = Strongly disagree	4	4.5
Total	89	100.0

Median score = 3

Question 3.10. Other benefits.

Responses to this question took the form of free text comments. These are discussed in the results and analysis section.

A6.1.4 Question 4: *'In what specific medical conditions or situations do you feel ACP might be useful?'*

Question 4.1. Cancer

	Frequency	Per cent
Yes	84	94.4
No	5	5.6
Total	89	100.0

Question 4.2. Dementia

	Frequency	Per cent
Yes	85	95.5
No	4	4.5
Total	89	100.0

Question 4.3. Frailty

	Frequency	Per cent
Yes	68	76.4
No	21	23.6
Total	89	100.0

Question 4.4. Heart failure

	Frequency	Per cent
Yes	72	80.9
No	17	19.1
Total	89	100.0

Question 4.5. Stroke

	Frequency	Per cent
Yes	76	85.4
No	13	14.6
Total	89	100.0

Question 4.6. Terminal illness

	Frequency	Per cent
Yes	88	98.9
No	1	1.1
Total	89	100.0

Question 4.7. Other(s).

Responses to this question took the form of free text comments. These are discussed in the results and analysis section. A break down of these comments by type of condition or situation where participants considered ACP to be potentially useful is provided in the following table:

Conditions where ACP appropriate (no. of mentions)		
Respiratory	Neurological	Other
COPD (13) (4 mentioned 'severe / end stage / advanced')	Neurological conditions (10) (4 mentioned 'progressive / degenerative')	Any condition where patients would like to plan for future (1)
Respiratory failure (3)	Parkinson's (7)	Severe trauma (2)
Pulmonary fibrosis (1)	MND (9)	Any chronic or life limiting condition (7)
	Huntington's (1)	Any condition affecting capacity (1)
	MS (10)	Congenital disease (1)
	Brain injury (1)	Patients on the palliative care register (1)
	Early stages of dementia (3) (2 mentioned 'before capacity lost')	Renal conditions (1)
	ME (1)	Everyone (4)
	Severe learning disability (1)	Liver failure (1)
	Cerebral palsy (1)	Extreme old age / well elderly (2)
	Movement disorders (1)	Any condition affecting speech or communication (1)
		Diabetes in the elderly (1)
		IHD (1)

A6.1.5 Question 5: *'What do you feel is generally the best time to carry out ACP with patients in primary care?'*

Question 5.1. As early as possible

	Frequency	Per cent
1 = Strongly agree	10	11.4
2	26	29.5
3	33	37.5
4	16	18.2
5 = Strongly disagree	3	3.4
Total	88*	100.0
Median score = 3	*1 missing value	

Question 5.2. Around the time of a new (significant) diagnosis.

	Frequency	Per cent
1 = Strongly agree	11	12.6
2	39	44.8
3	21	24.1
4	15	17.2
5 = Strongly disagree	1	1.1
Total	87*	100.0
Median score = 2	*2 missing values	

Question 5.3. At a time of relative wellness.

	Frequency	Per cent
1 = Strongly agree	11	12.6
2	48	55.2
3	19	21.8
4	7	8.0
5 = Strongly disagree	2	2.3
Total	87*	100.0
Median score = 2	*2 missing values	

Question 5.4. Routinely, above a certain age threshold.

	Frequency	Per cent
1 = Strongly agree	4	4.6
2	8	9.2
3	16	18.4
4	44	50.6
5 = Strongly disagree	15	17.2
Total	87*	100.0
Median score = 4	*2 missing values	

Question 5.5. Routinely, in certain medical conditions.

	Frequency	Per cent
1 = Strongly agree	12	13.8
2	43	49.4
3	20	23.0
4	8	9.2
5 = Strongly disagree	4	4.6
Total	87*	100.0
Median score = 2		*2 missing values

Question 5.6. At other times.

Responses to this question took the form of free text comments. These are discussed in the results and analysis section.

A6.1.6 Question 6: *'What do you feel are the important practical and ethical problems with ACP?'*

Question 6.1. ACPs may be difficult to interpret.

	Frequency	Per cent
1 = Strongly agree	4	4.5
2	47	53.4
3	26	29.5
4	9	10.2
5 = Strongly disagree	2	2.3
Total	88*	100.0
Median score = 2		*1 missing value

Question 6.2. ACPs may be difficult to apply in practice.

	Frequency	Per cent
1 = Strongly agree	10	11.5
2	43	49.4
3	23	26.4
4	10	11.5
5 = Strongly disagree	1	1.1
Total	87*	100.0
Median score = 2		*2 missing values

Question 6.3. ACPs may conflict with clinical opinion.

	Frequency	Per cent
1 = Strongly agree	10	11.4
2	46	52.3
3	26	29.5
4	5	5.7
5 = Strongly disagree	1	1.1
Total	88*	100.0
Median score = 2		*1 missing value

Question 6.4. It is difficult to find the right time for ACP.

	Frequency	Per cent
1 = Strongly agree	11	12.6
2	47	54.0
3	21	24.1
4	7	8.0
5 = Strongly disagree	1	1.1
Total	87*	100.0
Median score = 2		*2 missing values

Question 6.5. If left too late, patients may lack capacity to do ACP.

	Frequency	Per cent
1 = Strongly agree	36	40.9
2	48	54.5
3	4	4.5
4	0	0
5 = Strongly disagree	0	0
Total	88*	100.0
Median score = 2		*1 missing value

Question 6.6. May not be available in the right place at the right time.

	Frequency	Per cent
1 = Strongly agree	15	17.2
2	45	51.7
3	23	26.4
4	4	4.6
5 = Strongly disagree	0	0
Total	87*	100.0
Median score = 2		*2 missing values

Question 6.7. It is difficult to predict future wishes for ACP.

	Frequency	Per cent
1 = Strongly agree	8	9.2
2	44	50.6
3	27	31.0
4	8	9.2
5 = Strongly disagree	0	0
Total	87*	100.0

Median score = 2 *2 missing values

Question 6.8. Patients may change their mind after making an ACP.

	Frequency	Per cent
1 = Strongly agree	14	15.9
2	40	45.5
3	24	27.3
4	7	8.0
5 = Strongly disagree	3	3.4
Total	88*	100.0

Median score = 2 *1 missing value

Question 6.9. Patients may be coerced into making decisions.

	Frequency	Per cent
1 = Strongly agree	7	8.0
2	26	29.5
3	37	42.0
4	13	14.8
5 = Strongly disagree	5	5.7
Total	88*	100.0

Median score = 3 *1 missing value

Question 6.10. ACP might be used to save the NHS money.

	Frequency	Per cent
1 = Strongly agree	7	8.0
2	18	20.5
3	31	35.2
4	16	18.2
5 = Strongly disagree	16	18.2
Total	88*	100.0

Median score = 3 *1 missing value

Question 6.11. Other problems with ACP.

Responses to this question took the form of free text comments. These are discussed in the results and analysis section.

A6.1.7 Question 7: *'What do you feel are the important barriers to making ACPs?'***Question 7.1.** ACP is not equally available to all patients.

	Frequency	Per cent
1 = Strongly agree	15	17.2
2	39	44.8
3	24	27.6
4	9	10.3
5 = Strongly disagree	0	0
Total	87*	100.0
Median score = 2		*2 missing values

Question 7.2. Clinicians are uncomfortable with discussing ACP.

	Frequency	Per cent
1 = Strongly agree	15	17.0
2	40	45.5
3	20	22.7
4	12	13.6
5 = Strongly disagree	1	1.1
Total	88*	100.0
Median score = 2		*1 missing value

Question 7.3. People don't know about ACP.

	Frequency	Per cent
1 = Strongly agree	20	22.7
2	45	51.1
3	19	21.6
4	3	3.4
5 = Strongly disagree	1	1.1
Total	88*	100.0
Median score = 2		*1 missing value

Question 7.4. ACP takes up too much time.

	Frequency	Per cent
1 = Strongly agree	13	14.8
2	33	37.5
3	25	28.4
4	14	15.9
5 = Strongly disagree	3	3.4
Total	88*	100.0
Median score = 2		*1 missing value

Question 7.5. ACP is too expensive.

	Frequency	Per cent
1 = Strongly agree	1	1.2
2	7	8.1
3	31	36.0
4	32	37.2
5 = Strongly disagree	15	17.4
Total	86*	100.0
Median score = 4		*3 missing values

Question 7.6. Other barriers.

Responses to this question took the form of free text comments. These are discussed in the results and analysis section.

A6.1.8 Question 8: *'Would you like to have an ACP for yourself?'***Question 8.1.** I would like to have my own ACP.

	Frequency	Per cent
1 = Strongly agree	24	28.2
2	24	28.2
3	21	24.7
4	7	8.2
5 = Strongly disagree	9	10.6
Total	85*	100.0
Median score = 2		*4 missing values

Question 8.2. I am likely to make my own ACP in the next year.

	Frequency	Per cent
1 = Strongly agree	1	1.2
2	4	4.7
3	18	21.2
4	18	21.2
5 = Strongly disagree	44	51.8
Total	85*	100.0
Median score = 5		*4 missing values

Question 8.3. I would advise close family members to make ACPs.

	Frequency	Per cent
1 = Strongly agree	12	14.1
2	33	38.8
3	26	30.6
4	9	10.6
5 = Strongly disagree	5	5.9
Total	85*	100.0
Median score = 2		*4 missing values

Question 8.4. I have already made my own ACP.

	Frequency	Per cent
Yes	1	1.2
No	82	98.8
Total	83*	100.0
*6 missing values		

A6.1.9 Question 9: *'How do you think we might best improve use of ACP in primary care?'*

Question 9.1. Involve other healthcare professionals in providing ACP

	Frequency	Per cent
1 = Strongly agree	31	34.8
2	42	47.2
3	12	13.5
4	3	3.4
5 = Strongly disagree	1	1.1
Total	89*	100.0
Median score = 2		*1 missing value

Question 9.2. More training for clinicians in ACP

	Frequency	Per cent
1 = Strongly agree	34	38.2
2	45	50.6
3	8	9.0
4	1	1.1
5 = Strongly disagree	1	1.1
Total	89	100.0
Median score = 2		

Question 9.3. More publicity on ACP

	Frequency	Per cent
1 = Strongly agree	34	38.2
2	47	52.8
3	6	6.7
4	1	1.1
5 = Strongly disagree	1	1.1
Total	89	100.0
Median score = 2		

Question 9.4. Make ACP a routine part of care

	Frequency	Per cent
1 = Strongly agree	21	23.6
2	35	39.3
3	21	23.6
4	9	10.1
5 = Strongly disagree	3	3.4
Total	89	100.0
Median score = 2		

Question 9.5. Make available a brief pro-forma for ACP

	Frequency	Per cent
1 = Strongly agree	27	30.7
2	38	43.2
3	15	17.0
4	6	6.8
5 = Strongly disagree	2	2.3
Total	88*	100.0
Median score = 2		*1 missing value

Question 9.6. Other ideas for improvement.

Responses to this question took the form of free text comments. These are discussed in the results and analysis section.

A6.1.10 Question 10: *'Do you have any other comments or thoughts on ACP in primary care which you would like to draw to our attention?'*

Responses to this question took the form of free text comments. These are discussed in the results and analysis section.

A6.2 Effect of respondent characteristics on questionnaire responses

A6.2.1 Effect of sex on responses

Question 2.8. I feel confident in assessing patients' mental capacity to participate in ACP

	Sex (per cent)		
	Male	Female	
1 = Strongly agree	9 (26)	9 (17)	18
2	14 (41)	10 (19)	24
3	10 (29)	17 (31)	27
4	1 (3)	13 (24)	14
5 = Strongly disagree	0	5 (9)	5
Total	34	54	88*
Median	2.00	3.00	
Mann-Whitney U = 554.000, Z = -3.220, p = 0.001			

*1 missing value

Question 9.2. More training for clinicians in ACP

	Sex (per cent)		
	Male	Female	
1 = Strongly agree	8 (24)	25 (46)	33
2	21 (62)	24 (44)	45
3	3 (9)	5 (9)	8
4	1 (3)	0	1
5 = Strongly disagree	1 (3)	0	1
Total	34	54	88*
Median	2.00	2.00	
Mann-Whitney U = 696.500, Z = -2.105, p = 0.035			

*1 missing value

Question 9.3. More publicity on ACP

	Sex (per cent)		
	Male	Female	
1 = Strongly agree	7 (21)	27 (50)	34
2	21 (62)	25 (46)	46
3	5 (15)	1 (2)	6
4	0	1 (2)	1
5 = Strongly disagree	1 (3)	0	1
Total	34	54	88*
Median	2.00	1.50	
Mann-Whitney test: U = 595.500, Z = -3.091, p = 0.002			

*1 missing value

A6.2.2 Effect of age on responses

Question 5.3. At a time of relative wellness

	Age range (per cent)				
	31-40	41-50	51-60	61-70	
1 = Strongly agree	7 (37)	1 (4)	3 (8)	0	11
2	11 (58)	11 (48)	22 (58)	2 (100)	46
3	0	8 (35)	8 (21)	0	16
4	1 (5)	2 (9)	4 (11)	0	7
5 = Strongly disagree	0	1 (4)	1 (3)	0	2
Total	19	23	38	2	82*
Median	2.0	2.0	2.0	2.0	
Kruskall-Wallis H = 13.967, df. 3, p = 0.003					

*7missing values

Question 9.2. More training for clinicians in ACP

	Age range (per cent)				
	31-40	41-50	51-60	61-70	
1 = Strongly agree	15 (75)	7 (30)	10 (26)	1 (50)	33
2	5 (25)	13 (57)	23 (59)	1 (50)	42
3	0	3 (13)	4 (10)	0	7
4	0	0	1 (3)	0	1
5 = Strongly disagree	0	0	1 (3)	0	1
Total	20	23	39	2	84*
Median	1.0	2.0	2.0	1.5	
Kruskall-Wallis H = 14.889, df. 3, p = 0.002					

*5 missing values

A6.2.3 Effect of number of years in current role on responses

Question 6.2. ACPs may be difficult to apply in practice

	Years in position (per cent)				
	1-10	11-20	21-30	31-40	
1 = Strongly agree	4 (14)	1 (5)	4 (15)	0	9
2	13 (46)	7 (35)	16 (62)	0	36
3	7 (25)	7 (35)	6 (23)	1 (100)	21
4	3 (11)	5 (25)	0	0	8
5 = Strongly disagree	1 (4)	0	0	0	1
Total	28	20	26	1	75*
Median	2.0	3.0	2.0	3.0	

Kruskall-Wallis H = 8.279, df. 3, p = 0.041

*14 missing values

Question 9.2. More training for clinicians in ACP

	Years in position (per cent)				
	1-10	11-20	21-30	31-40	
1 = Strongly agree	17 (61)	5 (25)	8 (29)	0	30
2	10 (36)	13 (65)	14 (50)	1 (100)	38
3	1 (4)	2 (10)	4 (14)	0	7
4	0	0	1 (4)	0	1
5 = Strongly disagree	0	0	1 (4)	0	1
Total	28	20	28	1	77*
Median	1.0	2.0	2.0	2.0	

Kruskall-Wallis H = 9.497, df. 3, p = 0.023

*12 missing values

A6.3 Clinician questionnaire internal consistency

Theme	Cronbach's alpha
Experience of ACP	$\alpha = .863$
I have encountered patients with ACP in primary care	
I have been involved in helping patients make ACPs	
Confidence / knowledge about ACP	$\alpha = .862$
I am familiar with the concept of ACP	
I feel confident in helping patients make ACPs	
I feel confident in assessing patients' mental capacity to participate in ACP	
I am familiar with professional guidance on ACP	
I am confident in my understanding of legislation governing the use of ACP	
Supportive of ACP in primary care	$\alpha = .917$
I am in favour of the concept of ACP	
It is important to offer patients ACP in primary care	
GPs should be involved in ACP (their role is important)	
I would want to be involved in this process (time and expertise permitting)	
We should do more ACP in primary care	
Positive about benefits of ACP	$\alpha = .901$
Helps communication (clinicians / patients / relatives / carers)	
Reduces stress / anxiety in patients	
Reduces stress / anxiety in relatives / carers	
Gives patients control over their future care	
Makes decision making easier for clinicians	
Makes decision making easier for relatives / carers	
Reduces inappropriate investigations / treatments	
Reduces inappropriate hospital admissions	
Saves healthcare costs	

A6.4 Questionnaire for Practice Managers: quantitative data and analysis

A6.4.1 Question 1: *'How many patients do you have registered at your practice?'***Question 1. Registered patients**

No. patients	Freq.	No. patients	Freq.
1900	1	8300	1
3000	1	8400	1
3100	1	8943	1
4517	1	8967	1
4756	1	9170	1
4758	1	9500	1
5400	1	9950	1
5600	1	10000	1
5800	1	11200	1
5826	1	11500	1
5966	1	11750	1
6023	1	12000	1
6302	1	12740	1
6500	1	14000	1
7956	1	14900	1
8165	1	16000	1
8200	3	16700	1
		Missing	1
		Total	37

Mean registered patients = 8450

A6.4.2 Question 2: *'Are you familiar with the concept of ACP (as we have described it)?'***Question 2. Familiarity with concept**

	Frequency	Per cent
Yes	35	94.6
No	2	5.4
Total	37	100.0

A6.4.3 Question 3: *'Does your practice have a system for recording when patients have an advance care plan?'*

Question 3. Recording of ACPs

	Frequency	Per cent
Yes	28	75.7
No	5	13.5
Don't know	4	10.8
Total	37	100.0

Median = 1 ('yes')

A6.4.3.1 Question 3a: *'If yes, please specify.'*

Responses to this question took the form of free text comments. These are discussed in the results and analysis section.

A6.4.4 Question 4: *'Does your practice have any process for review of ACPs?'*

Question 4. Process for review of ACPs

	Frequency	Per cent
Yes	11	29.7
No	19	51.4
Don't know	7	18.9
Total	37	100.0

Median = 2 ('no')

A6.4.4.1 Question 4a: *'How often are ACPs reviewed?'*

Responses to this question took the form of free text comments. These are discussed in the results and analysis section.

A6.4.4.2 Question 4b: *'What process is used?'*

Responses to this question took the form of free text comments. These are discussed in the results and analysis section.

A6.4.5 Question 5: 'Please could you estimate the number of patients with ACPs in your practice? If possible, please run a computer search. (Suggested Read codes are at the end of questionnaire.)'

The following table displays figures supplied by Practice Managers for the number of patients in their practice with ACPs, along with any comments or qualification of these figures, alongside the number of patients on the practice register as well as any other comments made by the participants considered relevant to the number of patients likely to have ACPs.

Number of patients with ACPs*	Practice register	Relevant comments
Formal 19. informal >30 on the palliative register	8200	GSF Going for Gold Programme
0 (but I was unaware of the read code until now)... We do have patients identified for this to be given to – incidentally they are not cancer patients. Our community nurse is tasked with issuing them.	4756	-
29	12000	Palliative care meeting
59 PPC 90 DNARS	16000	Residential nursing homes pilot nurses
2 (active)	11750	
30	8400	Palliative care meeting
209 on cancer register, also end stage COPD and other conditions	-	-
37 with 'not for resus' completed but have only 12 records of preferred place of care coded.	8165	Working with MacMillan nurses
Approx 20	6302	-
20	9950	-
5	4517	-
24	5400	-
75	12740	-
14	9500	-
51 (41 DNAR)	8200	-
5	1900	-
46	16700	Multidisciplinary GSF end of life meetings
7	5826	-
0 patients with ACP, 18 with 'Not for resuscitation'	8943	Gold Standards meeting
50	8967	MDT meeting

*17 missing values

A6.4.6 Question 6: *'Do your clinical staff have access to any ACP documents to assist with carrying out ACP?'*

Question 6. Access to ACP documents

	Frequency	Per cent
Yes	23	62.2
No	5	13.5
Don't know	9	24.3
Total	37	100.0

Median = 1 ('yes')

A6.4.7 Question 7: *'Does your practice have any information leaflets or posters to inform patients about ACP?'*

Question 7. Information for patients

	Frequency	Per cent
Yes	11	29.7
No	20	54.1
Don't know	6	16.2
Total	37	100.0

Median = 2 ('no')

A6.4.8 Question 8: *'Do you have any other comments or thoughts on ACP in primary care which you would like to draw to our attention?'*

Responses to this question took the form of free text comments. These are discussed in the results and analysis section.

GLOSSARY

Advance care planning

A formal process of decision making whereby a capable person, that is one who has the ability to make the relevant decisions, is able to establish choices about healthcare in advance of a potential future state of incapacity. Increasingly used as an umbrella term for other elements of anticipatory decision making such as **living wills**, in current usage in the UK this may result in the individual making an **advance statement of wishes**, **advance decision to refuse treatment** or appointing someone with **Lasting Power of Attorney**.

Advance decision to refuse treatment

As provided for in the UK in the Mental Capacity Act 2005, a legally binding refusal of treatment, made in advance, which can include refusal of life sustaining treatment.

Advance directive (advance healthcare directive)

Similar to advance care planning, this usually describes a document or statement in which an individual establishes choices about healthcare in advance of a potential future state of incapacity. A term previously used in the UK, and in continued use in other countries including the US, Canada and Scotland, it may refer to two elements, **living wills** or instructional advance directives, and **proxy advance directives**.

Advance statement of wishes

A non binding statement of preferences or wishes for future care, intended to be later considered when assessing ‘best interests’.

Best interests

This principle, referred to in the Mental Capacity Act 2005, requires that every effort is made when making decisions affecting people who lack capacity, to ensure that they are as close as possible to the decisions the individuals would have made themselves.

Capacity

See **mental capacity**: the ability of people to make autonomous decisions.

Competence

This is the ability of people to make autonomous decisions. Competence is the term previously used in the UK to describe this ability, which is now referred to as **mental capacity**. The term competence is still used in many countries including the US.

Durable Power of Attorney

See **Lasting Power of Attorney for health and welfare**. This is the US legal term for a **surrogate decision maker**.

Enduring Power of Attorney

See **Lasting Power of Attorney for health and welfare**. Conferring authority only for financial decisions, this was the legal term previously used in the UK for **surrogate decision makers**.

End of life care

Care provided to individuals with terminal conditions in the final days, weeks or months of life, focusing on pain and symptom control and trying to ensure that patients live as well as possible until the end of their lives. See also **palliative care**.

General Practice (family medicine)

A medical specialty usually based in **primary care**, providing front line general medical care to patients as their first point of contact with healthcare services.

Lasting Power of Attorney for health and welfare

As provided for in the UK in the Mental Capacity Act 2005, this allows an individual to appoint someone to make decisions on his behalf with regard to health and welfare in the case of future loss of capacity. Provision is also given in the Mental Capacity Act 2005 for Lasting Powers of Attorney for property and affairs, giving the holder authority to make decisions about financial matters. Various other general terms have been used, including ‘**surrogate or substitute decision maker**’ and ‘**healthcare proxy**’ or ‘**proxy advance directive**’. The current legal term in the US is **Durable**

Power of Attorney, and the previous related legal term in the UK was **Enduring Power of Attorney**.

Living will

Essentially what is now defined in the UK as an **advance decision to refuse treatment**, the term living will, also sometimes referred to as an instructional advance directive, continues to be used in the US and Canada amongst other countries. In some areas, in addition to being understood as a legally binding advance refusal of treatment, it may also include non binding statements of wishes for future care.

Mental capacity

This is the ability of people to make autonomous decisions. Mental capacity was previously referred to in a medical and legal sense as ‘competence’, with this term still used in many countries including the US. A test of mental capacity is provided in the Mental Capacity Act 2005.

Old Age Psychiatry

A medical specialty within that of Psychiatry, focusing on the particular needs of older people with psychiatric disorders, including the specific problems associated with cognitive impairment and dementia.

Palliative care

A medical specialty based on the holistic care of patients with advanced, progressive illness, focusing on active management of pain and other distressing symptoms as well provision of psychological, social and spiritual support. See also **end of life care**.

Proxy advance directive (healthcare proxy)

See also **surrogate decision maker**. This is where a person is appointed by an individual, with the authority to make decisions on behalf of that individual in the event of loss of capacity. See also **Lasting Power of Attorney for health and welfare**, **Durable Power of Attorney**, **Enduring Power of Attorney**.

Primary care

The first point of contact with healthcare services, primary care in the UK, usually refers to general practice. Focusing on general and holistic care of patients, primary care deals with a broad range of physical, psychological and social problems. See also **General Practice**.

Secondary care

Healthcare services provided to patients by specialists, generally based in hospitals, usually upon referral from **primary care**.

Surrogate (substitute) decision maker

A person, appointed by an individual, with the authority to make decisions on behalf of that individual in the event of loss of capacity. Also sometimes known as a **healthcare proxy**. See also **Lasting Power of Attorney for health and welfare**, **Durable Power of Attorney**, **Enduring Power of Attorney**.

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