Views and Practices of Anaesthetists Towards End of Life Decisions and Advance Care Planning

Dr Douglas Hector Blackwood

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Centre for Perioperative Medicine

Division of Surgery & Interventional Science

Supervisors

Dr Cecilia Vindrola-Padros

Professor David Walker

Professor Michael Mythen

Declaration

I, Douglas Hector Blackwood confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

Background: Despite low mortality rates, ~2%, the high volume of surgery now conducted in the UK means that around 100,000 people die each year within 90 days of having an operation. It is probable that these patients would have benefited from a discussion about their wishes and preferences prior to the operation via a process of advance care planning. Pre-operative assessment clinics, commonly operated by anaesthetists, offer an opportunity for this prior to surgery.

Aim: This thesis aims to describe the most important components of end-of-life and advance care planning discussions as well as barriers which may prevent anaesthetists from engaging in these conversations pre-operatively.

Methods: A mixed methods study was carried out to outline the knowledge, attitudes, and practices of UK anaesthetists towards end-of-life decisions and advance care planning in the perioperative setting. This involved multiple workstreams: two systematic reviews; two national surveys of UK anaesthetists; and a qualitative component involving semi-structured interviews and participant observation.

Results: UK anaesthetists were found to be knowledgeable and have a good understanding of advance care planning. They have positive attitudes towards the concept both generally and perioperatively, and strongly support the principle of autonomy. When considering their own end-of-life care the themes which emerged were: *'patient engagement'*; *'intensity of treatment'*; *'family and friends'*; a *'transition point'*; *'care'*; and plans for *'after death'*. Perioperative advance care planning was not a routine part of anaesthetists' practice as the treatment limitations implied were not felt to align with surgical care. The structure and organisation of pre-operative care also creates barriers to anaesthetists having these discussions.

Conclusion: This study has demonstrated that advance care planning is not a routine part of UK anaesthetists' practice for patient's approaching surgery and outlines particular attitudinal and practical barriers. It describes a process for a modified advance care planning discussion appropriate for surgical patients.

Impact Statement

When a person becomes critically unwell they often lose the capacity to make decisions (1,2). The individual is thus excluded from decisions about their treatment unless their wishes have been discussed and/or documented in advance; a process known as advance care planning (ACP).

Despite low mortality rates, ~2%, the high volume of surgery in the UK means that around 100,000 people die each year within 90 days of an operation (3). With an ageing and more co-morbid population (4) there will likely be greater numbers of complications and an increased risk of dying (5). These patients will likely benefit from ACP pre-operatively when cognition is intact. Since 2001 a small number of studies (6–13) have trialled perioperative ACP but it has not become common practice.

Healthcare is a complicated social system. It is the sum of multiple actions by many individuals (14) and changing behaviours to improve outcomes is difficult (15). Frequently, quality improvement projects fail (16) because they do not take into account the multiple influences on an individual's behaviour (17,18). This study was designed to discover and describe these influences and outline barriers which prevent anaesthetists from engaging in end-of-life (EoL) and ACP discussions. This has allowed for recommendations which adapt to the expertise and beliefs of clinicians and offer solutions to remove identified barriers.

Perioperative ACP will require a redesign of ACP specifically for the surgical setting. This study highlights that ACP, with a focus on treatment limitations and EoL care, is unlikely to be adopted. This is because of the general positivity created by the low risk of death; the often-reversible nature of surgical complications; and the belief that treatment limitations are often indicative that surgery itself is inappropriate. However, pre-existing discussions about whether to proceed with surgery could be modified to include some components of ACP. Slight changes to these discussions to include information about the level of *'patient engagement'* desired, the role of *'family and friends'*, and a patient's minimally acceptable quality of life would be useful at a later date should the patient suffer complications and lose capacity. An emphasis on an ultimate outcome would allow for the flexibility desired by clinicians when making *'best interests'* decisions.

There are two major barriers which prevent anaesthetists engaging in these discussions: the cultural focus of pre-assessment clinics on physical health; and a lack of clarity over the role of the anaesthetist in the patient's journey towards surgery. The creation of a separate *'high-risk'* clinic could help ameliorate both. The *'high-risk'* clinic would require appropriate physical space and would schedule sufficient time for in-depth discussions. It would shield the anaesthetist from the multiple other tasks and queries in pre-assessment clinics which can interrupt and crowd out long discussions. Referral to the *'high-risk'* clinic should be made when surgery is first considered and should come directly from the surgical team. This would counteract the idea that the anaesthetist is *"not invited"* to the conversation and early referral would allow this discussion to feed into the decision-making process.

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Abbreviations

ACP	Advance Care Planning
AD	Advance Decision
AMA	American Medical Association
CPR	Cardiopulmonary Resuscitation
CVI	Content Validity Index
DNACPR	Do Not Attempt Cardio-Pulmonary Resuscitation
EPaCCS	Electronic Palliative Care Coordination Systems
GRADE	Grading of Recommendations, Assessment, Development and Evaluations
HSCP	Health and Social Care Professional
I-CVI	Individual-Content Validity Index
ICM	Intensive Care Medicine
ICU	Intensive Care Unit
IHI	Institute for Healthcare Improvement
KAP	Knowledge, Attitudes, and Practice Study
LCP	Liverpool Care Pathway
LPA	Lasting Power of Attorney for Health and Welfare
MCA	Mental Capacity Act (2005)
MDT	Multi-Disciplinary Team
MMAT	Mixed Methods Appraisal Tool
MRC	Medical Research Council
NELA	National Emergency Laparotomy Audit
NHS	National Health Service
NICE	National Institute for Health and Care Excellence

NIH	National Institutes of Health
ONS	Office for National Statistics
OSCE	Objective Structured Clinical Examination
PAC	Preoperative-Assessment Clinic
POSSUM	Physiological and Operative Severity Score for the enUmeration of Mortality and Morbidity
PSDA	Patient Self-Determination Act
RCoA	Royal College of Anaesthetists
RCOA-MEP	Royal College of Anaesthetists Membership Engagement Panel
RCT	Randomised Control Trial
REC	Research Ethic Committee
RRT	Renal Replacement Therapy
S-CVI	Scale-Content Validity Index
SDM	Shared Decision Making
SORT	Surgical Outcome Risk Tool
SRQR	Standards for Reporting Qualitative Research
TPB	Theory of Planned Behaviour
VOICES	Views of Informal Carers – Evaluation of Services
WFS	World Fertility Survey
WHO	World Health Organisation

Glossary

Anaesthetist	A medical practitioner competent in the art, science and practice of anaesthesia (adapted from the Charter of the RCoA (19)).
Health and social care professionals	Individuals who maintain health in humans through the application of the principles of evidence-based medicine and caring (adapted from a definition previously used by the WHO (20)).
High-intensity treatments	Medical interventions including CPR, inotropic support, renal replacement therapy, and mechanical ventilation.
High-risk patients	A group of patients with increased risk of mortality post-surgery. This group is characterised by advancing age, having a greater number of co-morbidities, having major or complex surgery, and being more likely to have emergency surgery (21).
Knowledge, attitudes, and practice study	A quantitative method (predefined questions formatted in standardised questionnaires) that provides access to quantitative and qualitative information (22)
Perioperative period	The moment from when the decision to undergo surgery has been taken until the patient has returned to best health and no longer requires specialist input (adapted from RCoA document *'Perioperative Medicine: The pathway to better surgical care'*(23)).
Shared decision making	A collaborative process whereby HSCPs support patients in reaching decisions about treatments (24).

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1 Introduction

1.1 A Historical Perspective

In recent years there have been a multitude of independent reviews (25,26); audits (27); surveys (28); and investigations (29,30) which have highlighted variable and at times inadequate care for individuals approaching the end of life (EoL). Clearly, caring for dying patients is not a problem novel to the 21st century, however, the last two hundred years have seen significant changes in the timing, causes, and location of death. Life expectancy has doubled from around 40 years in 1841 (31) to around 80 years by 2017 (31). Prior to the twentieth century the most likely cause of death was acute infection (32) and 15% of infants would die before their first birthday (31). Slower deaths, as the result of chronic diseases of the circulatory and respiratory systems, or indeed cancer, were much rarer (32). The picture today in developed countries is the reverse. Death now normally follows a period of chronic illness such as cancer, heart disease, stroke, respiratory disease, or diseases of the nervous system (32,33). Deaths of younger people and children have become vanishingly rare accounting for less than 10% of all deaths (33). The latter half of the twentieth century also witnessed a growing hospitalisation of death and by the 1960's 40% of all deaths occurred in hospitals (34,35). Despite this, it wasn't until 2008 that the Department of Health first published a national strategy for EoL care (36). The development of medicine and healthcare has occurred in parallel with care for the dying; related but not integrated. This historical legacy provides some explanation for why it remains such a challenge to provide excellent EoL care in a hospital setting (28,37).

1.1.1 Death in the 19th And Early 20th Century

In the 19th century death was understood in the context of religion and the time before death was spent on spiritual preparation, providing an opportunity for one to reaffirm faith and atone for sins. Prayer and reading from scripture provided family with a comforting role (38). In an age prior to the expansion of hospitals, and when hospitals were viewed as akin to poorhouses, families sought to keep their ill relatives at home believing the care they would receive would be superior (38). 85% of deaths still occurred at home by 1900 (36). At this time, doctors had little to offer dying patients, apart from perhaps, a good bedside manner and alcohol and opium for symptom relief

(38). However, as the 19th century progressed, and with scientific advances such as the creation and marketing of morphine in 1817 and the invention of the hypodermic needle in 1857, a greater role for physicians in the care of the dying appeared to be approaching (38). It was not one however which was always enthusiastically embraced. Patients who were labelled *'incurable' or 'terminal'* tended to be avoided by doctors and hospitals, with the American Medical Association (AMA) having to draw up a code in 1847 asking doctors not to abandon the incurably ill or those imminently dying (38). Of course, some physicians and surgeons took an active interest in the care of the dying, however, the influence of these enthusiasts was not sufficient to generate change (38). As the twentieth century dawned there was a great expansion in the number and prestige of hospitals which sought medical progress and the treatment of disease (39). Those without hope of recovery had to rely on special institutions which were established, often by religious orders, called *'hospices'* or *'homes for the dying'* (39). Religious thinking and practice dominated the running of these *'homes'*, with the doctors who did work there seemingly disinclined from sharing their experiences with a wider medical audience (39). The number of these *'homes'* grew in the early twentieth century but they were by no means widespread and the majority of people continued to die at home (39).

1.1.2 The Introduction of the National Health Service

The greatest change in medicine within the UK was the establishment in 1948 of the National Health Service (NHS) (40). Following the success of the planned economy during the war, societal problems, including illness, were seen as technical challenges which could be fixed by the application of a determined and competent government. This was perhaps best epitomised by Aneurin Bevin when he introduced the National Health Service Bill to Parliament and stated that he *"would rather be kept alive in the efficient if cold altruism of a large hospital than expire in a gush of sympathy in a small one"* (41,42). The mantra of Britain's welfare state was of care from *'the cradle to the grave'*, however in practice it provided scant attention to the latter with its focus on the widespread acute and chronic health problems of a population recovering from war (43).

Two major reports outlined the conditions in which many in the UK died during the 1950s (35,44). The first was a national survey of district nurses caring for cancer patients living in their own home (34). It described dreadful conditions of suffering and physical deprivation (42,44). This spurred the Marie Curie Memorial to open homes for the care of terminally ill cancer patients and provide a night nursing service (34). It did not produce any systematic response from government, a fact which was investigated by Glyn Hughes in his report *‘Peace at the Last’* (35). This highlighted that the majority of deaths continued to occur at home; in nursing homes; or in the *‘homes for the dying’* run by charitable and religious organisations. Outside of hospital there was a lack of funding and appropriately trained staff who could provide the *“standards which could reasonably be expected”* (34,35). Both reports also allude to the wider societal changes in family values which were impacting care at EoL: Many General Practitioners (GPs) believed that the introduction of the NHS was a cause of families becoming less willing to look after their unwell relatives (34,35). More broadly there was a recognition of competing priorities in a modern society, with more people moving to new towns and the suburbs, and the requirements of work preventing the care of long-term unwell family members (34,35,44).

The general silence about the care of the dying in the medical literature in the 1800s had continued well into the 1950’s: “*few talked about it, wrote about it or were taught anything about it as students”* (45). The doctors who did offer a public opinion had a paternalistic approach. They believed that the judicious use of morphine was all that could be done, that this should be at the discretion of the doctor, and its role in hastening death should be shrouded in secrecy from patient and family (43,46,47). Despite this, inadequate pain relief was common place, partly through a bizarre fear that the patient would become addicted or because of the worry that it would shorten life (43,45,48). In regard to the latter, in 1957 a general practitioner, Dr Adams, was charged with, but acquitted of, the murder of an elderly patient to whom he had administered a lethal dose of opiates. In his summing up to the jury Devlin J stated that the doctor was *“entitled to do all that was proper and necessary to relieve pain and suffering even if the measures he took might incidentally shorten life”* (49). This introduced into English law the *“double-effect”* principle (50).

1.1.3 The Modern Hospice Movement

Dame Cicely Saunders is widely acknowledged as the founder of the modern hospice movement and of palliative medicine (51). Originally a nurse, her interest in the care of the dying was triggered when caring for a dying Jewish émigré, David Tasme in the London Hospital in 1947 (52). Informed that she was unlikely to achieve her ambition of the widespread improvement of the care of the dying as a nurse she was encouraged to read medicine (42). Whilst volunteering as a nurse at a *'home for the dying'* she qualified as a doctor in 1957 and began seven years of clinical care and research at St Joseph's Hospice (42). As a medical student she published a case series of patients with advanced cancer including sections describing general management; nursing; the terminal stage; and managing pain (52,53). During the following 10 years St Christopher's Hospice was planned and built. The would mark the beginning of the modern hospice movement when it opened in 1967 (54). An article in the British Hospital Journal outlined the goal that the hospice *'will try to fill the gap that exists in both research and teaching concerning the care of patients dying of cancer and those needing skilled relief in other long-term illnesses and their relatives'* (52). When initially developing the idea of St Christopher's in the early 1960's Saunders envisioned it as both a religious endeavour and as a means of improving the medical care of the terminally ill (55). Partly for reasons of funding, this religious aspect was side-lined, although not completely abandoned. With the receding importance of religiosity to the vision, greater effort was fostered on professional development with Saunders publishing articles, books, and developing an international professional network which would be crucial in the later dissemination of hospice principles (55). Initially St Christopher's was funded solely by charitable donations, however greater professional and political recognition of the importance of care for the dying meant that by 1970 the NHS contributed 2/3 of its running costs, including fully funding the research programme and outpatient service (52). At the same time other hospices, modelled on St Christopher's, were beginning to emerge across the country (52) with 94 founded between 1970 and 1984 (56). Two established national charities, Macmillan and Marie Curie, joined with the growing hospice movement to provide support and funding for the field of palliative care (57).

1.1.4 Palliative Care Medicine

Alongside the growth of charitable hospices there was the development of hospital support teams for terminal care from 1976. Between 1982-1996 the number of hospitals with either a multidisciplinary palliative care team or a palliative care clinical nurse grew from 5 to 275 (56). NHS inpatient units also grew in number but continued to be outnumbered by charitable hospices by a ratio of three to one (36). The 1980 Wilkes report argued that hospices were not affordable in terms of money or personnel and encouraged the adoption of the principles of terminal care throughout the NHS (58). In practice this did little to stem the growth of the charitable hospice sector, however, it was a landmark as it was the first national report to recognise terminal care as an issue requiring governmental policy (56). By 1987 district health authorities were required to take the lead on planning and coordinating services for terminally ill patients and in 1989 funding began to be earmarked for hospice services (56). The 1995 Calman-Hine report, which proposed the restructuring of cancer services, also made recommendations about embedding palliative care within cancer teams and integrating these with general practice (59).

At the same time as the importance of care for the dying began to be recognised by government and the NHS the structure of palliative care within the medical profession started to be formalised. Initially, hospice doctors were GPs or hospital specialists who developed an interest in the care of dying patients (52). The 1980's saw the formation of a medical association in order to support its practitioners (Association for Palliative Medicine for Great Britain and Ireland), the establishment of a scientific journal (Palliative Medicine) and the recognition of palliative medicine as a sub-specialty with the subsequent development of a specific training programme (52).

1.1.5 Where We Are Now

2008 saw the first national strategy for EoL care in England (36) and this was quickly mirrored by specific approaches for each of the devolved nations (60–62). At the time there was concern that the profile and priority of EoL care remained low and that this was contributing to reports of people experiencing unnecessary pain; not being treated with dignity and respect; and many not dying in the location they would choose (36). The strategy focussed in particular on encouraging greater open discussion between patients, family members, and health and social care professionals (HSCPs). It highlighted the need for appropriate care planning; greater coordination between services and locations; greater access to services 24/7; better training for HSCPs to ensure maximal comfort and support for patients and families; and better bereavement support for families after a patient has died (36). The strategy set out to address these issues and was accompanied with a significant increase in funding (36).

Following from this there was an increase in the number of people dying at home or in a care home (viewed as a proxy for patient choice) (63); the development of national quality standards (64); the introduction of Electronic Palliative Care Coordination Systems (EPaCCS) to record and communicate patient’s wishes (63); the introduction of the VOICES (Views of Informal Carers – Evaluation of Services) survey of bereaved relatives (63); and an improvement in the gathering and dissemination of information to those commissioning and providing EoL care (65). The, now abandoned, Liverpool Care Pathway (LCP) was also promoted and adopted following the 2008 strategy (63).

The LCP provided alerts, guidance, and a structured, single record for doctors, nurses and multidisciplinary teams who were inexpert in palliative care (25). From 2012 the LCP began to receive substantial criticism in the media (66) triggering the government to commission Baroness Neuberger to chair an independent review of the use and experience of the LCP in England (25). The review recognised that, in the right hands, the LCP could provide a model of good practice for the last days or hours of life for many patients, but, in the wrong hands the LCP had been used as an excuse for poor quality care (25). They concluded that a generic protocol, as the LCP had come to be seen, was the wrong approach and that it should be replaced with an individual EoL care plan, informed by good practice guidance (25).

Despite the creation of the hospice movement, the development of Palliative Medicine as a medical specialty, and the attention of national governments, in recent years there has continued to be evidence of variable and at times inadequate care at EoL (27,28,30,37). The deficiencies are many of those identified in the 2008 strategy: staff failing to recognise patients are dying resulting in poor care planning (27,30); poor symptom control (27,30); poor communication between staff and patients and families (27,30); inadequate out of hours services (30); and poor coordination of care (28). This has resulted in multiple reports (26,67–69) attempting to outline the path to improving EoL care. They all have slightly different foci however they graduate to similar themes: that care is delivered by competent and compassionate staff; that it is coordinated; that good quality care is free from discrimination and available to all; that it should maximise comfort and wellbeing; and that it is of paramount importance that individuals should be offered choice in their EoL care, including the location and type of care they would choose to receive. For this to be possible it requires honest and informed conversations at a stage early enough for these choices to be actioned and recorded in a manner that might guide others should they lose capacity. (26,67–69).

1.2 Advance Care Planning

Advance care planning (ACP) has been consistently recognised as an important mechanism for ensuring this goal of person-centred care is achieved and that communication and decision-making between patient and HSCPs is made more effective. ACP is supported in the General Medical Council (GMC) guidance *'Treatment and Care Towards End of Life'* (70) and has recently been recommended by the National Institute for Health and Care Excellence (NICE) (71). The first national guidance for HSCPs in the UK was published in 2007 (72) and has been most recently reviewed in 2014 (73).

1.2.1 The Need for Advance Care Planning

The nature of illness is one that often causes cognitive impairment and/or unconsciousness resulting in a lack of capacity to make treatment decisions (1,2,74). Raymont et al. (1) estimated that 40% of all acute medical admissions did not have mental capacity to make treatment decisions, and Murphy et al. (74) found that 28% of all hospital inpatients lack capacity. It is likely that patients who are approaching EoL would have even higher rates of incapacity. Indeed, a retrospective analysis of patients in the United States who died found that 43% required a treatment decision to be made prior to their death and 70% of these patients lacked capacity to make this decision (2). This places HSCPs in a difficult position as it requires them to make decisions for an individual thereby diminishing, or removing, the patient's autonomy.

HSCPs in Europe (75), North America (76) (77,78), Asia (79), and Australasia (80) all report providing non-beneficial or futile care to patients at EoL. A US study of 1136 critically ill patients found that the physicians caring for them felt that 11% were perceived as receiving futile treatment and a further 8.6% were perceived as receiving probably futile treatment (81). Similar data is available from a study of European and Israeli Intensive Care Units (ICUs) where 16% of doctors and nurses felt they were providing excessive treatment to at least one patient they were currently caring for (82). An audit of care from hospitals in Australia found that investigations such as blood tests were ordered for 40% of people after it was documented that death was likely without a clear rationale for how this would change treatment (83). A lack of readily available and clear documentation of patient's wishes has been described as one reason why such non-beneficial, or futile, care is provided as it often leads to HSCPs taking the least *'risky'* course of action when presented with an unfamiliar patient who is acutely unwell (84).

1.2.2 Ethical Foundations of Advance Care Planning

Autonomy is one of the prima facie *'four principles'*: the others being justice, beneficence, and non-malfeasance (85). These comprise the generally accepted normative theory[*] (86) of biomedical ethics. Autonomy is the *"ability and tendency to think for oneself, to make decisions for oneself about the way one wishes to lead one's life based on that thinking, and then to enact those decisions"* and has been termed *'first among equals'* within these four principles (85). It is well encapsulated in the phrase *'no decision about me, without me'* which was used in the 2010 UK government white paper *'Equity and Excellence: Liberating the NHS'*. This sought to make shared decision making (SDM) the norm in the NHS (87).

SDM should be a collaborative process whereby HSCPs support patients in reaching decisions about treatments. The conversation should bring together HSCPs' expertise including available treatment options, evidence, risks, and benefits, with a patient's preferences relating to personal circumstances, goals, values, and beliefs (24). However, for SDM to occur the patient must be able to consider and weigh the information presented to them by HSCPs and communicate their decision about their

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[*] A hypothesis, or other statement, about what is right and wrong, desirable and undesirable, just or unjust in society.

treatment. It is clear that for many people at times of illness, and particularly when approaching EoL, this is not possible (1,2,74). ACP provides a mechanism for individuals to establish decisions about future care that take effect when they lose the capacity to make informed decisions (88).

1.2.3 The Origins and Legal Basis for Advance Decisions

The idea of an individual indicating in writing ahead of time the extent to which one would consent to treatment, a *'living will'*, was first proposed by the Euthanasia Society of America in 1967 (89). The *'living will'* was gradually incorporated into law in the United States over the following 20 years so that by 1986 41 states had adopted them (89). *'Living wills'* had many shortcomings, particularly the narrow range of situations and decisions to which one document could apply. In response another legal tool, the *'power of attorney'* was refashioned to allow for another person, *'an attorney*', to make healthcare decisions should an individual be incapacitated and unable to make a decision for themselves (89). Again, lawmakers in the United States started to make provisions for this, so that by 1997 all states had some form of a healthcare power of attorney statute (89). It was not until 2005 that the UK had a similar statutory footing for medical advance decision making with the passing of the Mental Capacity Act (MCA) (2005) (90). Despite this lack of statute the concept of medical advance decision making was not unknown to English law prior to 2005 (91).

In *Re AK*, in 2001, the health trust treating a 19-year-old patient with Motor Neurone Disease, sought a declaration that it would be lawful to comply with his request to discontinue mechanical ventilation. He communicated his wishes by blinking his eye but was aware that as his condition progressed this would become impossible and asked to discontinue treatment, including mechanical ventilation, two weeks from the date he lost ability to communicate. The judge upheld the decision to stop mechanical ventilation declaring "*an advance indication of the wishes of a patient of full capacity and sound mind are effective"* (92). However, the burden of proof rested on those who sought to establish the existence and validity of any advance decision (AD) and when life was at stake it should be scrutinised with especial care (91). In the case of *HE v A Hospital NHS Trust* (93) Munby J granted a declaration seeking to give a blood transfusion to an incapacitated adult Jehovah's Witness who had previously signed an

AD refusing to receive the transfusion of blood or primary blood products. Whilst her mother and sister believed that the AD should be upheld her father declared that she had since given up her Jehovah's Witness faith and if able to choose would now not refuse blood products (93). The judge stated that *"if there is doubt that doubt falls to be resolved in favour of the preservation of life"* (93). Whilst the common law acknowledged ADs, even in cases of life sustaining treatment, it did so from a position of suspicion where a *'modicum of doubt'* raised against its validity appeared to be sufficient to trigger the bias in favour of preservation of life. In addition to the AD itself, further *'convincing'* and *'inherently reliable'* evidence was required for it to be upheld (91).

The MCA (90) came into effect in 2007 and established a statutory framework for decision making for incapacitated patients including for ADs. These decisions come in three forms which can come into effect when a patient loses capacity:

- Statements of wishes and feelings
- Advance decisions to refuse treatment (ADRT)
- Lasting Power of Attorney (LPA)

The MCA aimed to clarify the law and clearly define the requirements for an AD to be valid and the circumstances in which it may be deemed inapplicable (91).

1.2.4 What Is Advance Care Planning?

Interestingly, the term ACP is not used within the MCA (90), nor is it used in the Code of Practice (94) designed to provide help and guidance for HSCPs, carers, friends, and families. This gives weight to the claim that ACP and ADs are not synonymous. In the early 1990's, experience of *'living wills'* and *'powers of attorney'* in the United States had shown that these were recognised as an inadequate tool, if used alone, to ensure good decision making whilst caring for a terminally ill patient (95). A more global term of ACP was adopted with an emphasis on the broader process of communication among patients, their healthcare providers, their families, and important others regarding the kind of care that the patient would consider appropriate should they lack capacity (96). Whilst ADs may play a part in ACP they are an optional extra, with the process of communication, and not the completion of a form, of primary importance (96).

Since the coining of the term in 1994 (95), there have been multiple attempts to define and describe ACP in the literature (97–103). The two of greatest relevance to UK practice, are those of the GMC (70) (Box 1.1) and NHS Improving Quality (73) (Box 1.2).

Box 1.1 GMC Definition of Advance Care Planning

> *"The process of discussing the type of treatment and care that a patient would or would not wish to receive in the event that they lose capacity to decide or are unable to express a preference, for example their preferred place of care and who they would want to be involved in making decisions on their behalf. It seeks to create a record of a patient's wishes and values, preferences and decisions, to ensure that care is planned and delivered in a way that meets their needs and involves and meets the needs of those close to the patient."* (70)

Box 1.2 NHS Improving Quality Definition of Advance Care Planning

> *"Advance care planning is 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 or decisions relating to their care and treatment so that these can then be referred to by their carers (whether professional or family carers) in the event that they lose capacity to decide once their illness progresses. The legal context of advance care planning varies across the world.*
>
> *Under the terms of the Mental Capacity Act 2005 formalised outcomes of advance care planning might include one or more of the following:*
>
> - *advance statements to inform subsequent best interests decisions*
> - *advance decisions to refuse treatment, which are legally binding if valid and applicable to the circumstances at hand*
> - *appointment of Lasting Powers of Attorney ('health and welfare' and/or 'property and affairs').*
>
> *Not everyone will wish to make such records. Less formally, the person may wish to name someone whom they wish to be consulted if they lose capacity."*(73)

Multiple authors and organisations have produced frameworks for patients and HSCPs to guide the ACP process (104–112). UK advice from the GMC (70), Royal College of Physicians (RCP) (113) and NHS Improving Quality (73) recommend that ACP should broadly cover:

- What the patient understands is happening to their health and what will happen to their health in the future.
- Specific treatments they may wish to decline, being careful that they understand the implications (e.g. earlier death) of making these decisions.
- Family members, others close to, or legal proxies that the patient would want involved in decisions about their care.

Within this thesis the term advance care planning (ACP) is used to describe the process of discussion, which may or may not result in a written document. The term advance decision (AD) shall refer to any documentation of values, goals, concerns and/or preferences.

1.2.5 Evidence Supporting Advance Care Planning

As the goal of ACP is to maintain autonomy it has inherent value from both a legal and ethical standpoint. Similar to the process of consent it may not require additional *‘proof’* of benefit. However, given the potential of ACP to improve outcomes: quality of care; concordance with patient wishes; patient and carer satisfaction; and healthcare utilisation, it seems appropriate to ask whether this is supported by evidence.

In the last 10 years 14 systematic reviews, the largest including >100 papers, have been published assessing the efficacy of ACP (114–127). In summary, the relationship of ACP and outcome remains unclear. Many observational studies report a relationship between patients who have some form of AD with outcomes such as decreased hospital utilisation or increased patient and carer satisfaction. It is unsurprising that outcomes differ between these two groups given that the AD group is self-selecting for those who are willing to sacrifice time and effort to commit their wishes to paper. Although randomised control trial (RCT) data does exist it is programme and context dependant. Each programme has a different approach to the ACP process involving different specialties, discussion aides, timings, and patient populations which limits generalisability.

When developing their latest guidance recommending ACP (71) NICE reviewed the evidence supporting the use of ACP versus usual care in terms of outcome (88). The committee felt that even though the evidence was not of high quality ACP should be strongly recommended as it was not seen to have any obvious negative effects and would help to preserve dignity, enable patient choice, and does not involve a significant burden in terms of costs (88). The conclusion of this is that ACP is recommended in the UK for *"all patients approaching the end of life or at risk of a medical emergency"* (71).

1.3 Advance Care Planning in the Surgical Setting

Surgery, in developed countries, has reassuringly low mortality rates, 0.5 – 3.6% (128,129). Despite this, the high volume of surgery now conducted in the UK means that around 100,000 people die each year within 90 days of having a surgical procedure involving either general or regional anaesthesia (3). 32% of those over 65 who died in the United States in 2008 underwent an inpatient surgical procedure in the year before their death (130). It is probable that those patients who die in the period after surgery would benefit from having a discussion about their wishes and preferences prior to their operation. The benefit of such discussions would not be limited only to those who die in the immediate post-operative period. The 12-month mortality of all hospital inpatients is 29%, and whilst this is lower for surgical patients, 17%, it is nonetheless significant (131). A longitudinal study of UK civil servants showed that those who had a spell of sickness absence for a surgical operation were twice as likely to die in the following three years (132). Additionally, 16.8-26.9% (128,133,134) of surgical patients will suffer at least one complication. The presence of such complications has been shown to reduce both 1 and 5 year survival (133) as well as reducing future quality of life and psychosocial wellbeing (135). The *'making every contact count'* programme is a public health initiative which aims to use every patient encounter, even if not directly related, as an opportunity to promote positive health behaviours (136). In a similar manner, early conversations about priorities of care with patients undergoing surgery could help influence and direct treatment to that which is right for them. This could be applicable and useful in the 30 days, 12 months, 3, or 5 years following surgery.

1.3.1 The High-Risk Surgical Population

Clearly, not all surgeries, and not all patients, have an equal risk of dying postoperatively. Within the millions of patients who undergo surgery each year there is a *'high-risk'* population who, whilst comprising only 12.5% of the total number of surgical admissions, account for 84% of perioperative deaths (21). This group is characterised by advancing age, having a greater number of co-morbidities, having major or complex surgery, and being more likely to have emergency surgery (21). The REASON trial from Australasia found 30-day mortality for all types of surgery increased from 4% for patients in their 70's to 12% in the 90+ age group (5). In the UK, observational data from the National Emergency Laparotomy Audit (NELA) shows a 90 day mortality rate of <10% for those under 50 rising to 24% for the over 80's (137). This increased risk of mortality is likely a combination of the independent effect of increasing age (5) and that, as patients become older, they tend to have more co-morbidities (4). By the age of 50, half of the population have at least one morbidity, by the age of 65 most have at least two and by 75 most have at least three (4).

This *'high-risk'* population is likely to grow in size given that the population of the UK as a whole is getting older. In 2016 18% of the population were believed to be over 65 and this is projected to rise to 25% by 2046 (138). This mirrors the picture in other developed countries (139). Not only is this population growing but they are also undergoing more surgery and comprise a larger percentage of those having operations (140). The number of patients over 75 who underwent surgery in the UK almost doubled from 545,000 to 1,010,000 between 1999 and 2015 (140). By 2030 it is estimated that one fifth of the over 75 age group will undergo surgery each year (140).

1.3.2 Perioperative Medicine

In 2015 the Royal College of Anaesthetists (RCoA) launched its vision *'Perioperative Medicine: The pathway to better surgery'* (23). This has been driven by an understanding of the different needs of the high-risk surgical patient and an appreciation that their number will continue to grow (23).

Central to this vision is the role of SDM prior to surgery allowing both patient and doctor to make fully informed decisions and plan future care (23). Currently around 80% of those undergoing planned operations are being seen at an anaesthetic pre-operative assessment clinic (PAC) (141) but often these occur only weeks or days before surgery (142). A re-designed surgical pathway has been proposed with earlier engagement with patients, ideally, as soon as possible after the moment of contemplation of surgery (142). High-risk patients could then be identified and siphoned to a specialised *'high-risk clinic'* where perioperative physicians can explore beliefs, preferences, and options in a collaborative manner (142). This moment, where the patient is engaged and actively considering their current health, their goals, values, and priorities, could be ideal for discussing and documenting these via a concurrent process of ACP.

1.3.3 Perioperative Advance Care Planning

The idea of perioperative ACP is not a completely novel concept. In 2001 Grimaldo et al. published a RCT which involved having elective surgical patients receive, or not, a short information session stressing the importance of communication about EoL care between patients and their proxies (6). Since then a further seven studies have been published trialling perioperative ACP (7–13). These are summarised in Table 1.

Table 1 Summary of Studies Trialling ACP for Surgical Patients

Study	**Setting**	**Sample** **[] = n in intervention group**	**Intervention**	**Results**
Aslakson et al., 2019 (7) USA Design: RCT	Outpatient surgical oncology clinic at a single academic tertiary cancer centre.	92 [45] adult patients undergoing major cancer surgery.	Patients viewed an ACP video developed by patients, surgeons, palliative care clinicians, and other stakeholders.	Patient-centeredness of pre-operative consultations was unchanged although there were more ACP discussions in the intervention arm. No harm was noted. No change in patient Hospital Anxiety and Depression Scale (HADS) score; patient goals of care; patient and surgeon satisfaction or medical decision maker designation.
Briggs et al., 2004 (8) USA Design: RCT	Outpatient clinics at a single academic medical centre.	27 [13] adult patients with congestive cardiac failure, end stage renal disease or planned open heart surgery (n=8)	Facilitated patient-centred ACP interview to explore disease understanding and treatment preferences with patients and their surrogate.	Intervention improved concordance for treatment preferences between patient and surrogate. Intervention group had lower *‘decisional conflict’*[†]. Intervention group had higher perceived quality of communication.
Cooper et al., 2014 (9) USA Design: RCT	Outpatient preoperative clinic at single academic medical centre.	13 [8] adult surgical patients who were scheduled to have a post-operative stay on ICU.	Preoperative ACP discussion with the patient and surrogate to elicit the patient’s goals of surgery and values for perioperative treatment.	7 of 8 would recommend the conversation. 6 of 8 surrogates reported that the conversation helped prepare them for being a surrogate.

[†] The decisional conflict scale used in this study was designed to measure a state of uncertainty about the course of action to take.

Ernst et al., 2014 (10) USA Design: Retrospective pre-intervention / post-intervention cohort study	Outpatient clinics at a single Veterans Affairs hospital.	310 adult patients scheduled for a surgical procedure who were referred to palliative care.	Introduction of a systemwide frailty screening program.	Post-intervention there was an increase in palliative care consultations, and these were more likely to happen pre-operatively. This coincided with a 33% decrease in 180-day mortality.
Grimaldo et al., 2001 (6) USA Design: RCT	Outpatient preoperative clinic at a single academic centre.	200 [99] patients (>65 years) undergoing an inpatient surgical procedure.	A short 5-10-minute information session with an anaesthesiologist during their pre-operative clinic visit. These were designed to focus on the importance of communication between the patients and their designated proxies regarding EoL care.	87% of patients reported having discussions with their proxies as compared with only 66% of control patients (P> 0.001). The intervention also increased the durable power of attorney completion rate to 27% as compared with 10% completion rate by controls.
Song et al., 2005 (11) USA Design: RCT	Cardiothoracic surgery clinics at a single academic medical centre.	32 [16] patients (>50 years) scheduled for semi-elective cardiac surgery and their surrogates.	A 20-45-minute consultation with a trained nurse facilitator exploring disease understanding and treatment preferences with patient and surrogate.	Increased patient-surrogate congruence compared to control. Reduced patient's decisional conflict compared to control. No difference in anxiety between groups. No difference in knowledge of ACP.
Swetz et al., 2011 (12) USA Design: Retrospective non-randomised cohort study	Inpatients at single academic medical centre.	19 [13] adult patients with end-stage heart disease consented for LVAD as destination therapy.	A palliative medicine consultation with a MDT of allied health professionals and a palliative physician. The palliative physicians reviewed goals of care and ADs with patients and/or families.	11 patients (85%) in the intervention had ADs compared to 3 (50%) in the control.

Yang et al., 2004 (13) USA Design: Retrospective non-randomised cohort study	Single academic medical centre.	252 [74] adult patients undergoing elective exploration for possible pancreaticoduodenectomy or oesophagectomy.	Presence of AD on admission.	Review of notes revealed no identifiable impact of the AD on the care patients received in their subsequent hospitalisation.

1.3.4 Barriers to Perioperative Advance Care Planning

Despite twenty years of interest, perioperative ACP remains uncommon (143). It has been hypothesised that there is inherent resistance to ACP within surgical culture. Doctors from surgical specialties have been shown to feel less positively towards ADs than those from Emergency Medicine, Paediatrics, Obstetrics & Gynaecology, and Anaesthesia (144). Indeed, a survey of US surgeons, who routinely perform high-risk operations, found that 54% would decline to operate on a patient with an AD which would limit life-supporting therapy (143). Another survey found that 63% of surgeons would not honour a patient's request to withdraw life sustaining treatment following an operation complicated by hemiplegic stroke and respiratory failure (145).

The temperament of a surgeon has been described as one requiring optimism and confidence (146). Ethnographic research has found that surgeons have a different view of their relationship to patients than other doctors (147–150). Surgeons define their relationship with their patient as a promise to *'battle death'* on their behalf (146,147) and that this commitment is part of their identify as a surgeon (147). Death is seen very much as a *'failure'*, often a personal failure to the patient, and therefore something that must be avoided at all cost (148). Surgeons express feelings of *'ownership'* and *'personal responsibility'* to their patients (147,150) and also culpability when the operation is not successful (148). The has led to the description of *'surgical buy-in'*: a complex process by which surgeons negotiate with patients a commitment to, often burdensome, post-operative care before agreeing to undertake high-risk surgical procedures (148). When explicitly asked about perioperative ACP some surgeons view it as contradictory to the goals and values of surgery (148). They feel it would be a conflict of interest if a surgeon has to both advocate for aggressive surgical care and concurrently counsel the patient regarding EoL decisions (149). These attitudes, whilst almost certainly not universal, are ingrained enough to be recurrent themes of qualitative research (147–149) and are supported by the survey findings discussed above (143–145). They provide some explanation as to why perioperative ACP is not widespread. In their defence, it is a fair assumption that patients may not choose to be operated on by a pessimistic surgeon, unsure in their abilities who did not view their death following the operation as a failure (146). Surgeons, by assuming personal responsibility for the outcome of the operation and by conveying an expectation of success (150), likely bring comfort to their patients pre-operatively.

1.3.5 A Way Forward?

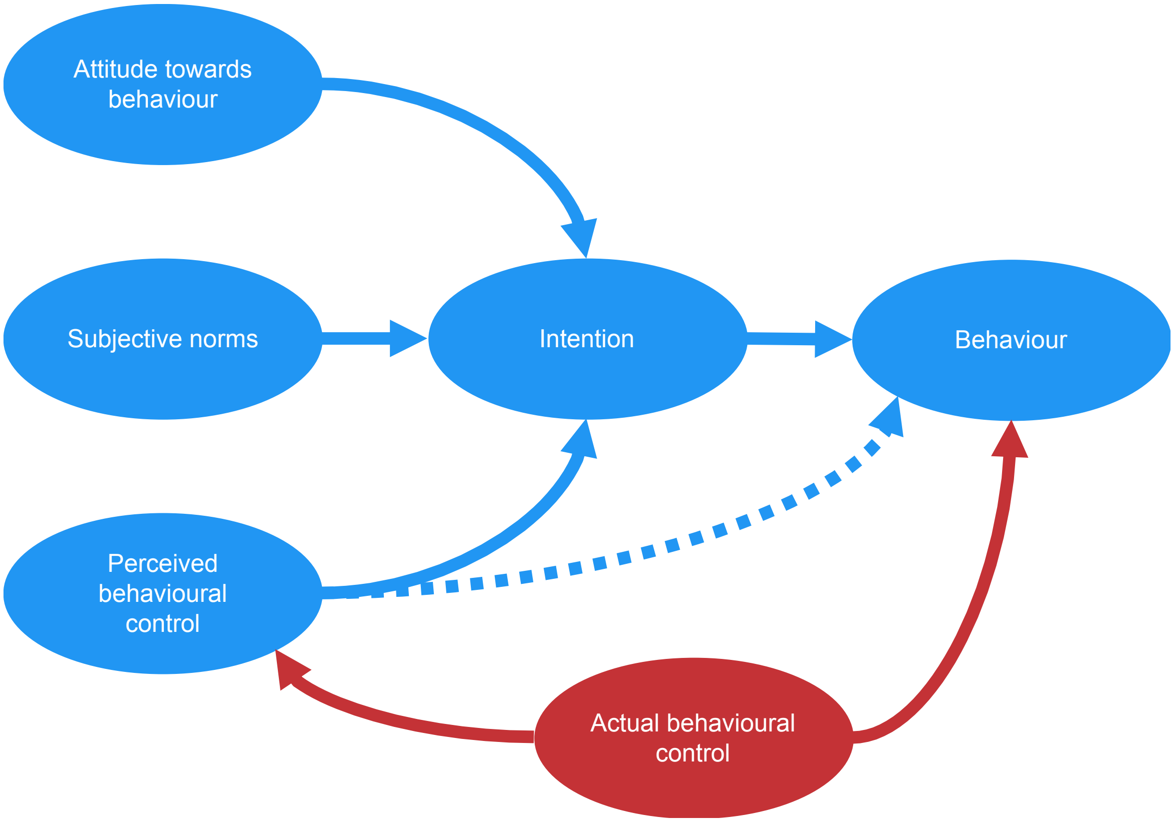
The RCoA's vision of perioperative medicine is one which promotes multi-disciplinary provision of care with doctors from anaesthesia, surgery, acute medicine, cardiology, and care of the elderly all taking the lead depending on the patient and context (23). For the reasons above, it may well be that surgeons are not optimally placed to have perioperative ACP discussions and that in some circumstances this role should fall to another specialty. Anaesthesia is the largest in-hospital specialty accounting for 16% of all hospital consultants (151). Whilst surgeons may be expert in prognosis following the operation, anaesthetists may have greater knowledge of the risks relating to frailty, co-morbidities, and recovery following major surgery (142). Additionally, UK anaesthetics training mandates a minimum of 9 months working in Intensive Care Medicine (ICM) and often, due to *'on-call'* commitments, time spent on the ICU is even greater (152). This provides an in-depth understanding of the realities of high-intensity medical treatments. For patients who are at high-risk of complications and subsequent critical illness this would provide an important perspective. Anaesthetists would seem to combine a knowledge of perioperative risk and an understanding of ICM with the opportunity to begin the process of ACP pre-operatively at PACs.

1.3.6 Conceptual Framework

The reasons for the lack of uptake of perioperative ACP are likely multiple and complex. Traditional biomedical research aggregates data across a population in the hope that individual variation is minimised and an overall effect can be determined (153–155). This is the approach which has been evident in previous studies of perioperative ACP (Table 1). However, healthcare is a complicated social system and is the sum of multiple actions by many individuals (14). Understanding the drivers for individual behaviour is therefore critical to understanding how to deliver change and improvement. Social research often focusses specifically on the individual variation in terms of people, culture, and context in the belief that it is these which determine success or failure (153–155).

The theory of planned behaviour (TPB) is the most commonly cited theory in studies predicting HSCPs behaviour or behavioural intention (156). The TPB suggests that human behaviour is governed by three kinds of considerations: beliefs about the likely consequences of the behaviour (behavioural beliefs); beliefs about the normative expectations of other people (normative beliefs); and beliefs about the presence of factors that may improve or hinder performance of the behaviour (control beliefs) (157). In combination, attitudes towards behaviour, subjective norms, and perceived behavioural control lead to the formation of a behavioural intention and intention is assumed to be a direct antecedent of behaviour (157). The TPB constructs of attitude, subjective norms, and perceived behavioural control have been shown to account for ~30% of the variance in behavioural intention of HSCPs (17,18). In addition, for successful performance of behaviour there must be not only an appropriate intention but also sufficient ability, e.g. skills, resources etc., to be able to accomplish the task (actual behavioural control) (158) (Figure 1).

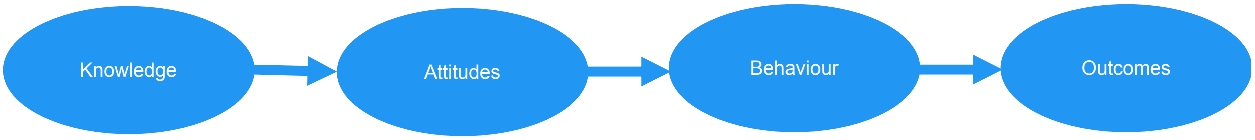
Figure 1 Theory of Planned Behaviour Diagram



Adapted from "Theory of Planned Behaviour Diagram" by I. Ajzen, 2019. Retrieved from http://people.umass.edu/aizen/tpb.diag.html#null-link. Copyright © Icek Ajzen 2019.

Within healthcare, Woolf (159) described a traditional knowledge, attitudes, and practice (or behaviour) (KAP) model (Figure 2) as a *'mechanism of action'* for how improved patient care can be achieved.

Figure 2 Traditional KAP Model



The assumption implicit in this model is that there is a linear relationship whereby improving knowledge, changes attitudes, alters behaviour, and improves outcomes. Assessed using the TPB this model is likely overly simplistic. Improved knowledge may have an impact on an individual's perceived behavioural control for example but may not change behaviour if they retain negative beliefs about how a behaviour will be seen by others (normative beliefs). Cabana et al. (160) adapted the traditional KAP model to map barriers to behavioural change when assessing physicians use of guidelines. Whilst the linear relationship of behavioural change of the traditional KAP model is questionable the use of knowledge, attitudes, and practice as a descriptive framework in order to map barriers to behavioural change is helpful to organise and categorise. The knowledge component includes understanding and/or training factors impacting both perceived and actual behavioural control; the attitude component includes personal beliefs and behavioural intention as well as beliefs surrounding subjective norms; and the practice component includes logistical factors which limit actual behavioural control as well as providing a measure of actual behaviour. I viewed the KAP framework as a more understandable method to design, frame, and categorise my results than a pure reading of the TPB, hence it is this approach I use throughout this thesis.

2 Methodology

2.1 Mixed Methods Research

As discussed in Section 1.3.6 healthcare revolves around individual decisions and behaviour. This will be true for perioperative ACP and therefore this topic is not one which could be adequately described by a single methodology. To try and capture as broad a view as possible I have adopted a mixed methods approach.

Mixed methods research has been defined as *"research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches … for the broad purposes of breadth and depth of understanding and corroboration"* (161). This approach allows for the development of *meta-inferences* (overall conclusions, explanations or understandings) which quantitative nor qualitative methods could do alone (162).

2.1.1 Background of Mixed Methods Research

Research utilising a mixture of quantitative and qualitative methods was evident in the work of anthropologists and sociologists in the first half of the 20th century, but the term *'mixed methods research'* was not coined or utilised until much later (161). Campbell & Fiske formalised this practice of using both quantitative and qualitative methods in a single study in 1959 (163). This article described the importance of '*convergence'* of research findings as a means of ensuring validity i.e. if results are replicated using differing methodologies (qualitative and quantitative) then they are more likely to be true and not the result of an error or bias in methodology. This use of multiple research methods as a way of measuring validity is known as *'triangulation'* (164); a term borrowed from naval science where multiple reference points are used to locate an object's position (165,166). Denzin defined triangulation as *"the combination of methodologies in the study of the same phenomenon"* (167). From this, three outcomes may arise: convergence, inconsistency, or contradiction (167). From any of these a superior explanation of the phenomena can be formed (161).

2.1.2 Rationale of Mixed Methods Research

In 1973 Sieber (168) described how the benefits of mixing methods went beyond triangulation and could be used to improve the design, data collection, and analysis of studies. Rossman & Wilson (169) highlighted three rationales for mixing quantitative and qualitative methods: *corroboration* through triangulation (discussed above); *elaboration* which provides richness and detail and can provide a different perspective on the same phenomenon; and *initiation*, where divergent results are sought in order to suggest areas for further analysis or to ultimately recast the research question.

In 1989 Greene et al. (170) reviewed the theoretical and empirical literature describing five purposes for mixing methods in a study (Table 2).

Table 2 Purposes for Mixing Methods in a Research Study

Triangulation	This is the traditional view which maintains that results from different methodologies can be combined as a way of corroborating the result of one with the other (170,171).
Complementarity	This seeks to elaborate, enhance, clarify, or illustrate results from one method with another. It could also be termed 'completeness' suggesting that a researcher can bring together a more comprehensive account by using both methodologies (170,171).
Development	This uses one methodology to help in the development and to better inform the research design of another e.g. using a qualitative focus group in the development of a questionnaire or scale (170).
Initiation	This occurs in the analysis phase where results may be contradictory. This should *'initiate'* interpretations and conclusions, suggest areas for future analysis or re-form the research question (169,170).
Expansion	This seeks to extend the breadth and range of an inquiry e.g. in evaluation of a program the use of qualitative methods to assess program processes and quantitative processes to assess outcomes (170).

Bryman (171) later expanded on this providing sixteen separate purposes although most of these could be included in the broader concepts of Greene et al. Two rationales which are distinct, as opposed to being sub-divisions of those of Greene et al., is that of *offset* and that of *diversity of views*. (171). '*Offset'* is the idea quantitative and qualitative methods have different strengths and weakness and that the weaknesses of one can be balanced by the strengths of the other (171). *'Diversity of views'* is described as combining researchers views represented by quantitative techniques and participants' perspectives by utilising qualitative techniques (171). In healthcare this may take the form of bringing together disciplines with different research backgrounds e.g. medicine is traditionally associated with more quantitative paradigms and nursing with qualitative paradigms (172).

2.1.3 The Paradigm Wars

Quantitative and qualitative methods are associated with paradigms which arise from quite different philosophical traditions. Paradigms of inquiry are worldviews that have distinctive ontological[‡], epistemological[§], and axiological[**] positions (173). These beliefs are basic and must be accepted on faith as it is not possible to establish their ultimate truthfulness (174).

Positivism / post-positivism is based on a worldview whereby an objective external reality exists (ontology); it is possible to observe this reality and remain independent from it (epistemology); and that values, morals, or ethics are extrinsic to this reality (axiology) (174,175). From this, anything which claims to be science must be a neutral activity. Those conducting research seek to eliminate all bias and preconception and research is to be based on pure observation that is free from the interests, values, and purposes of individuals (176,177). This is the traditional *'scientific method'* (178) where research is designed to try and prove (positivism) or disprove a hypothesis (post-positivism). The process attempts to be as *'mechanistic'* and objective as possible in order to confirm or refute a hypothesis (177). This is associated with quantitative methodologies (178) where the hypothesis can be assessed using instruments or observations which yield numerical data. This data is then analysed using descriptive or inferential statistical techniques in order to generalise findings onto a wider population (179). This desire is often for *'tangible'* results which allow for not only the explanation of social phenomena but also for the ability to discover causes and make predictions (176).

Constructivism / interpretivism focus on *subjective* reality (180), with emphasis on interpreting phenomena from the perspective of the individual and interpreting the world via meanings attached by the participants (169). It views reality as subjective and multiple as viewed by the participants (ontology); it maintains that researchers are necessitated to interact with their subjects as reality is '*constructed'* only in the mind of

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[‡] The form and nature of reality and what can be known about it.

[§] The relationship between the knower and what can be known

[**] The place of values, morals or ethics

the researcher during the investigation (181) (epistemology); and that the views and biases of the researcher are acknowledged and integrated into the analysis and results (174,182). This view states that, where social studies are concerned, it is not possible to ignore human beliefs, values, interests, or *'common sense'* (that which is said or done without thinking, questioning, or recognition) nor is it possible to truly separate observed from observer (177). As researchers are human beings studying the meaning of the actions of human beings they are both the subject and object of study (176). This worldview requires the researcher to seek complexity of views by using qualitative open-ended methods (178). As opposed to positivism where the researcher starts with a hypothesis and seeks to *deduce* its truth, constructivism requires researchers to inductively develop a theory (178).

Neither paradigm is without its inherent problems. A criticism of the qualitative paradigm is that it lacks approaches which minimise the risk of evaluator bias and it is not reproducible (180). From its relationship with the assumptions of interpretivism researchers have adopted an *'anything goes'* relativist approach and do not pay attention to the rationale for their interpretations (175). When taken to its extreme its relativist approach is logically self-refuting and prevents improvement. If reality truly lies in the eyes of the beholder with no interpretation of the world being of greater value than another, then research quality cannot be judged with any objectivity but must be accepted or dismissed on each individual's whim (183). Meanwhile, quantitative research, despite its value of objectivity, leaves much to the subjective fancy of the researcher e.g. the choice of what to study, the instrument or test used, the alpha level, the interpretation of data collected and when / how / if to publish results (183).

2.1.3.1 Solving the Paradigm Debate

The inherent differences between philosophies mean that some *'purists'* (169) consider qualitative and quantitative methodologies to be *"incompatible"* (177) given the different understanding of reality, truth, and the relationship between researcher and subject(s) (177). Positivism and interpretivism are as far apart as possible in terms of these philosophical fundamentals and as such one cannot believe both at the same time (174,184). However, even *'purists'* accept that whilst at a philosophical level there may be little room for accommodation it is not true that researchers are limited by their *‘worldview’* to only use quantitative or qualitative methods (174). One can hold the ontological, epistemological, and axiological views of interpretivism and still collect empirical information and vice versa (175). The assertion that there is a direct link between philosophical assumptions and research methods is not correct (184). A researcher can be faithful to either paradigm whilst collecting both quantitative and qualitative data (169).

‘Situationilists’ (169) believe that both paradigms have validity in different circumstances and that *“the problem under investigation properly dictates the methods of investigation”* (184). This belief does allow for the use of either method but maintains that they represent different conceptions of reality and for this reason cannot be mixed (169).

‘Pragmatists’ are unwilling to accept that *‘abstract’* paradigms should determine research methods, and instead insist the paradigms must demonstrate worth to the research method and researcher (177). It has been characterised as a *‘what works’* approach which ignores the constraints of a single philosophy or concept of reality (182). Ideas must be judged on their empirical and practical consequences, and from this paradigms must be judged on how they help us understand real world phenomena (183). This allows the use of different techniques and combinations of methods utilising the most useful aspects of each: *“If each technique has an inherent weakness, then it also has an inherent strength not matched the other techniques”* (168) . The goal of mixed methods therefore is to utilise the relative strengths of each technique in an attempt to understand phenomena (169).

Personally, I share the philosophy of *ontological pluralism* outlined by Johnson & Gray (185). It agrees with the ‘*qualitative’* approach that the thoughts, experiences, feelings, and emotions of individuals are real and therefore the world is composed of multiple ‘*subjective’* realities (perhaps better described as perspectives, opinions, or beliefs) (161). However, it also agrees with the ‘*quantitative’* view that there is an ‘*objective’* reality which impacts individuals regardless of their ‘*perspective’* (185). If one is knocked over by a bus it is not possible to construct another reality where this did not occur. Additionally, it is not a matter of opinion that one can or should drive on the left-hand side of the road in the UK (183). Language, institutions, and cultures are real (‘*intersubjective’*) and will give rise to objective reality regardless of whether they are ignored in favour of an individual's perspective. Attempts should be taken to understand these subjective, intersubjective, and objective realities as well as how they interconnect and relate (185).

2.1.4 Quantitative Methods

The primary instrument of quantitative social research is the '*survey'* as it lends itself to the objectivity, replicability, and statistical analysis demanded by the positivist or post-positivist paradigm (184). Its roots lie in the social surveys performed in Victorian Britain by social reformers such as Rowntree and Booth to collect data on poverty and working class life (186). They typically involve asking a subset of people questions on a specific topic and generalising to a larger population (187). In the health literature surveys generally examine health status (i.e. prevalence studies), identify risk factors, or chronicle activities, attitudes, or health outcomes (188)

A survey can be defined as a *"study that uses questionnaires to obtain data in a standardised format from respondents who answer the questions on behalf of themselves, others or a well-defined group"* (188).

In general, surveys are designed to provide a snapshot of how things are at a specific time. There is no attempt to control conditions or manipulate variables. They do not allocate participants into groups or vary the treatment they receive (186). Therefore, surveys are well suited to descriptive studies, but they can also be used to explore aspects of a situation, to seek explanation, or provide data for hypothesis testing (186). The latter are known as *'analytical'* (186) or *'explanatory'* (189) surveys.

It has been suggested that to avoid confusion the term *'questionnaire'* should be used to refer to the instrument (data collection tool) administered to respondents and *'survey'* to define the process of administering the questionnaire (189,190). This shall be adopted throughout this thesis.

2.1.5 Qualitative Methods

There have been many attempts to define qualitative research and determine whether it can, or should, be differentiated from quantitative research (191). There is no consensus on these questions, which is perhaps unsurprising as qualitative research is not a unified set of techniques or philosophies (191). In practice qualitative research is an umbrella term for a series of attitudes and strategies for conducting inquiry which aim to discern how people understand, experience, and create the social world (192). Creswell (193) has summarised the characteristics commonly espoused as being important when doing qualitative research (Table 3).

Table 3 Characteristics of Qualitative Research

Natural setting	Data is collected at the site where participants experience the issue or problem under study, not in a contrived environment like a laboratory. Information is gathered by direct interaction and observation within their context.
Researcher as key instrument	Qualitative researchers collect data themselves through examining documents, interviewing, and observations. They may use a protocol, but it is the researcher who actually gathers the information. Researchers tend not to rely on questionnaires or instruments developed by others.
Multiple sources of data	Qualitative researchers normally gather multiple forms of data e.g. interviews, observations, document analysis. All of this data is then analysed creating categories or themes which cut across all of the data sources.
Inductive data analysis	Qualitative researchers develop their themes from the *'bottom up'* as opposed to starting with a hypothesis they wish to prove or disprove.
Participants meanings	Focus should fall on the meanings that the participants hold about the problem or issue and not the meanings that the researcher, or previous researchers, have brought.
Emergent design	The initial plan for the research cannot be too tightly prescribed. All aspects of the research may change, including the question; participants; sites; and types of data collection, after researchers enter the field. The key idea is to learn from the issue or problem from the participants point of view and therefore the research must be able to adapt to these.
Theoretical lens	Qualitative researchers often use a lens to view their study e.g. gendered, racial, or class differences.
Interpretive inquiry	Qualitative research necessarily requires researchers to make an interpretation of the data they collect. This cannot be separated from their own biases. Unlike quantitative research these should be acknowledged but not minimised.
Holistic account	The goal of qualitative research is to develop a complex picture of the issue under study. This should include multiple perspectives and the multiple factors which are involved in a situation.

2.1.6 Use of Mixed Methods in Health Research

Traditionally, medical researchers have relied on quantitative methods to assess disease and health (172,194). In the 1980's qualitative researchers began to have more success in publishing their work in nursing journals and by the early 1990s top-tier nursing journals started to accept qualitative research (195). Between 2002-2011 qualitative studies increased from 6.8% to 15.1% of all papers published in top-ranked nursing journals (196). In the mid 1990's medical researchers also started to show a growing interest in qualitative methodologies (197). Major journals including the British Medical Journal (BMJ) (197), the Lancet (198), and the Journal of the American Medical Association (JAMA) (199,200) published overviews of and guidelines for qualitative research. Despite this, in 2000 only four of the top tier medical journals published a qualitative study (201) and qualitative research has continued to be poorly represented in the following years (202–204). This has started to improve with certain specialties leading the way. In 2017 qualitative research accounted for a quarter of submissions to the British Journal of General Practice (BJGP); had a similar acceptance rate for publication; and 10 of the 40 most highly cited BJGP articles of recent years employed qualitative methods (205).

At the same time as qualitative research started to become accepted within healthcare the idea of blending quantitative and qualitative methodologies was introduced (206,207). A review of health services research in England showed an increase in the number of studies classified as mixed methods from 17% in the mid 1990's to 30% in the early 2000's (208). With a growing attention in the literature to mixed methods research (209) leading research institutes, including the National Institutes of Health (NIH) in the United States (210) and the Medical Research Council (MRC) in the United Kingdom (211), have issued guidance and encouraged applications of mixed methods protocols.

The complexity of the phenomena investigated in healthcare research is such that it is often necessary to collect data using multiple methodologies in order to properly understand or evaluate them (206,212,213). Cultural and social factors have an impact on health through shaping personal behaviour; communication between patients and HSCPs; and by influencing society in regards to differing levels of prominence of health issues and allocation of resources (194). When trying to understand these factors contextual detail is important and is often lacking from purely quantitative data collection such as surveys (194).

Clarke and Yaros (206) describe how nursing research and nursing practice have both developed from the concept that nursing is both an art and a science involving different but complementary frameworks. In practice one would not rely solely on either objective, e.g. blood results, or subjective, e.g. patient history, data. Rather data from different perspectives are combined in order to give a more complete picture. If this logic is sufficient to guide the diagnosis and treatment of patients in the *'real world'* I would propose that it should be applicable to research also (206).

2.2 Study Design

The aim of this thesis is to describe the important components of EoL and ACP discussions and highlight barriers which may prevent such conversations in the perioperative period. This will be done using the viewpoint of anaesthetists. The ultimate goal of this thesis is to provide recommendations about the content of perioperative ACP discussions and strategies to mitigate any potential barriers. The research questions were designed using the conceptual framework detailed in Section 1.3.6 aiming to highlight the knowledge, attitudes, and practice of anaesthetists.

2.2.1 Research Questions

I. What is the knowledge, training, and understanding of ACP of anaesthetists?
II. What are the attitudes of anaesthetists towards their own EoL care?
III. What are the attitudes of anaesthetists towards ACP?
IV. What is the current practice of anaesthetists in regard to ACP?

2.2.2 Workstreams

Multiple workstreams were designed to answer the research questions.

Workstream	**Type**	**Code**
Advance Care Planning and End-of-Life Discussions in The Perioperative Period: A Review of Health and Social Care Professionals Knowledge, Attitudes, & Training	Systematic review.	SR-pACP
bigconversations: A National Survey of Anaesthetists' Preferences for their Own End of Life Care	National survey.	BC
Review of the Use of Knowledge, Attitudes & Practice Studies to Investigate Advance Care Planning	Systematic review.	SR-KAP
Knowledge, Attitudes, & Practice Survey of Advance Care Planning in the Perioperative Setting	National survey.	KAP-ACP
Qualitative Study using Ethnographic Methods	In-depth interviews and observations in a single centre.	QSE

The workstreams were inter-dependent and whilst each contributed individually to the overall research aim, they also informed one another. The exception to this was the SR-KAP which was necessary in order to create a well-evidenced questionnaire for use in the KAP-ACP. Results from the SR-KAP also fed into the QSE and added context to overall findings. These relationships are illustrated in Figure 3.

Figure 3 Interaction Between Workstreams

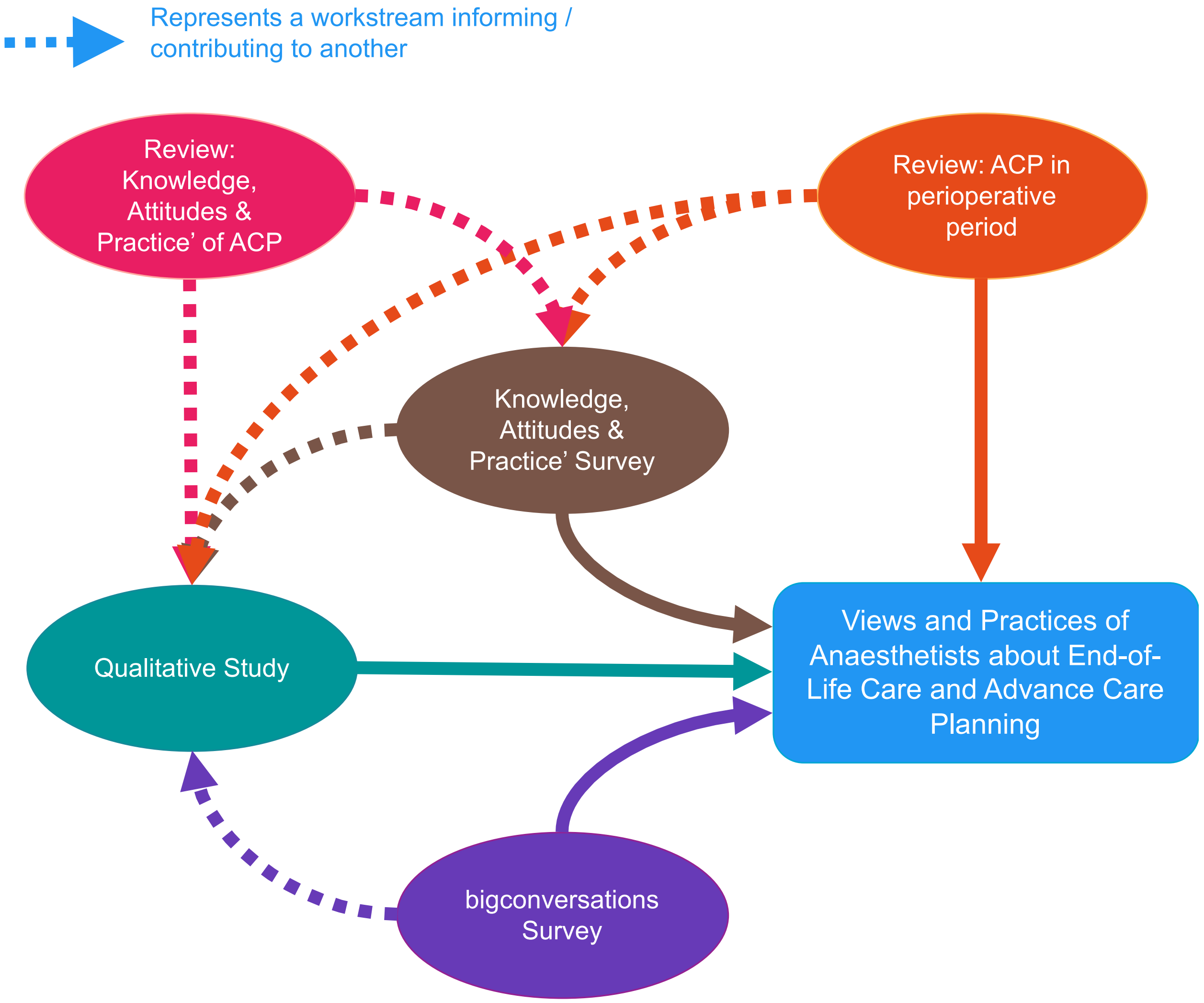


Table 4 Relationship Between Research Questions and Workstreams

Research Question	**Workstream**	**Chapter**
I. What is the knowledge, training, and understanding of ACP of anaesthetists'?	SR-pACP + KAP-ACP + QSE	3 + 6 + 7
II. What are the attitudes of anaesthetists towards their own EoL care?	BC	4
III. What are the attitudes of anaesthetists towards ACP?	SR-pACP + KAP-ACP + QSE	3 + 6 + 7
IV. What is the current practice of anaesthetists in regard to ACP?	KAP-ACP + QSE	6 + 7

2.2.3 Changes Following MPhil Upgrade

Following feedback from the external examiner during my MPhil to PhD upgrade the study was altered to give greater prominence to the QSE. Initially the QSE was only to comprise of semi-structured interviews. It was commented that this would have two limitations. Firstly, it would only allow the description of reported, as opposed to observed, behaviour. Secondly, there would be too great a *'weight'* on the quantitative workstreams in comparison to the qualitative. As such the QSE was redesigned to combine both semi-structured interviews and participant observation to mitigate these limitations.

2.2.4 Considerations for Study Design

2.2.4.1 Sequencing

Implementation of data collection refers to the sequence in which quantitative and qualitative data are collected (179). For this study an *explanatory sequential design* (178) was used which involved the collection of quantitative data followed by in-depth interviews and observations to elaborate, enhance, clarify, and better illustrate reality (214). Whilst there was overlap of the design stages of the different workstreams the results of the quantitative workstreams were available to inform the development of the qualitative study. The timeline of the various workstreams is presented in Figure 4.

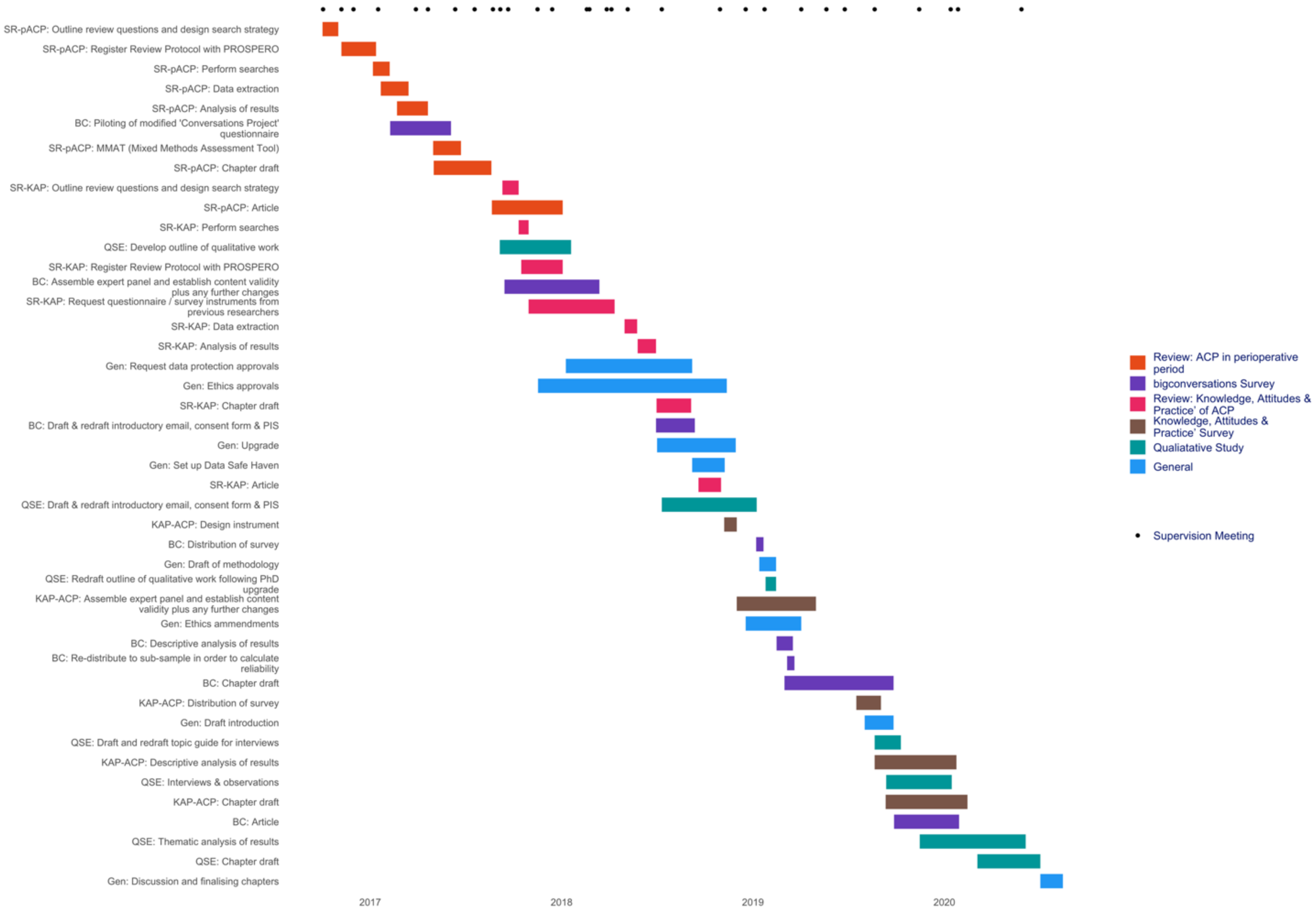
2.2.4.2 Priority

The *priority* given to the quantitative and qualitative components respectively is an important feature of mixed methods design (213). The quantitative workstreams were initially the primary focus of the study. This was a partially a pragmatic consideration given that medical audiences typically prefer quantitative data (179). As described above (Section 2.2.3) this was modified following the MPhil to PhD upgrade process. Whilst the quantitative workstreams still predominate the balance between the quantitative and qualitative components is more equal.

2.2.4.3 Integration

Another crucial design feature is the stage of the research process at which the quantitative and qualitative components are combined (214). There are four points of possible integration: within the research questions; within data collection; within data analysis; and during interpretation (179). Integration of quantitative and qualitative components in this study is evident primarily within the research questions and during interpretation. The research questions have been answered using both quantitative and qualitative methods. In Chapter 8 every effort has been made to integrate the findings of both the quantitative and qualitative workstreams into a complete explanatory narrative. Integration also occurred during data collection and analysis. Open-ended questions were included in the quantitative survey questionnaires and findings from these surveys were used to guide the qualitative study.

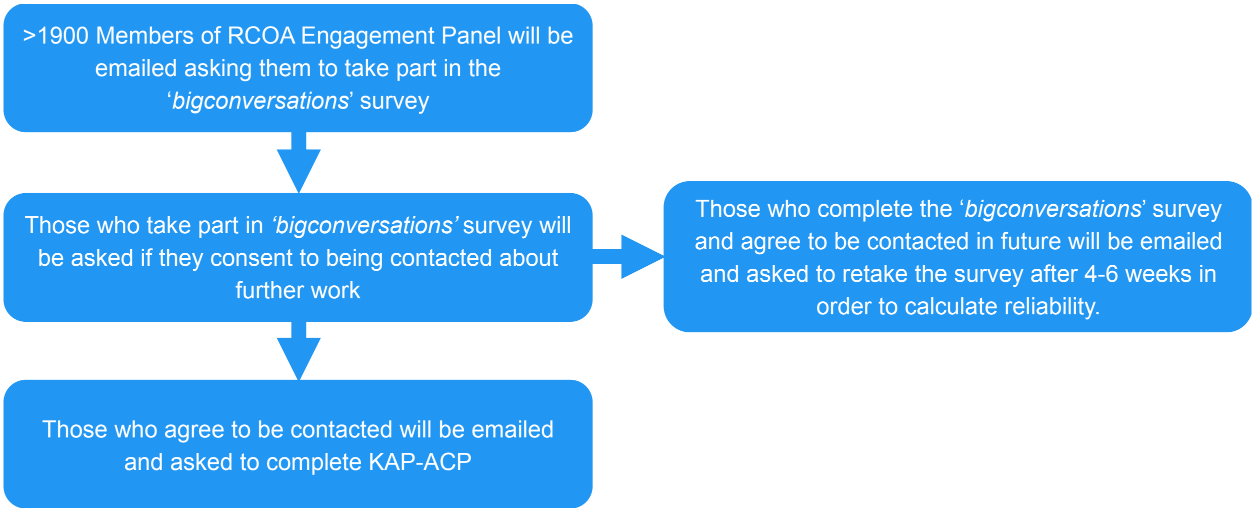
Figure 4 Study Timeline



2.2.5 Recruitment

The inclusion criteria for this study was anaesthetists. The definition of anaesthetists for this thesis is *'medical practitioners competent in the art, science and practice of anaesthesia'* which has been adapted from the Charter of the RCoA (19). Participants could be either practicing or retired. The latest RCoA census data from 2015 suggests that there are approximately 14,000 anaesthetists in the UK (215). For the quantitative workstreams (BC and KAP-ACP) recruitment was via the Royal College of Anaesthetists Membership Engagement Panel (RCoA-MEP). The RCoA-MEP is comprised of over 1,900 members and represents the diversity of anaesthetists in the UK. The model for recruitment for the BC and KAP-ACP is illustrated in Figure 5.

Figure 5 Recruitment Model for BC and KAP-ACP



For the QSE participants were selected via purposeful sampling from a single central London teaching hospital. The initial design planned to recruit participants from the RCoA-MEP using those who had agreed to be contacted about future work. When the QSE was redesigned to include participant observation this was changed in order to conduct all of the interviews in the same centre. This was to allow the observations and interviews to be interpreted together.

2.2.6 Ethical Approvals

This study was approved by the University College London Research Ethics Committee (study reference number: 12469/001). The NHS Health Research Authority decision tool (216) was used to determine if NHS Research Ethic Committee (REC) approval was required. NHS REC approval was determined to not be required.

For surveys, where personal identifiers such as names are not collected or are easily removed, written consent is often not gathered (217). The introductions for the BC and KAP-ACP questionnaires both stated that consent for data being used for specified purposes was implied from participating in the survey. This is normal practice for most large-scale surveys such as those undertaken by government departments in the UK (217).

Audio recordings of interviews were made on a passcode protected iPhone. These recordings were then sent to a transcription service (Essential Secretary Ltd.) for transcription. The transcriptions were anonymised with any identifiable comments redacted. The original audio recordings were destroyed following transcription.

Methods for handling and storing data were compliant with all data protection legislation including the EU General Data Protection Regulation (GDPR) (218). GDPR defines personal data as any information relating to an identified or identifiable natural person (218). Data could not be collected anonymously as an email address was required, and had to remain linked to the participants answers (including special category data about race, health status, and religion), so that data could be paired to allow calculation of test-retest reliability and to provide demographic data for the KAP-ACP.

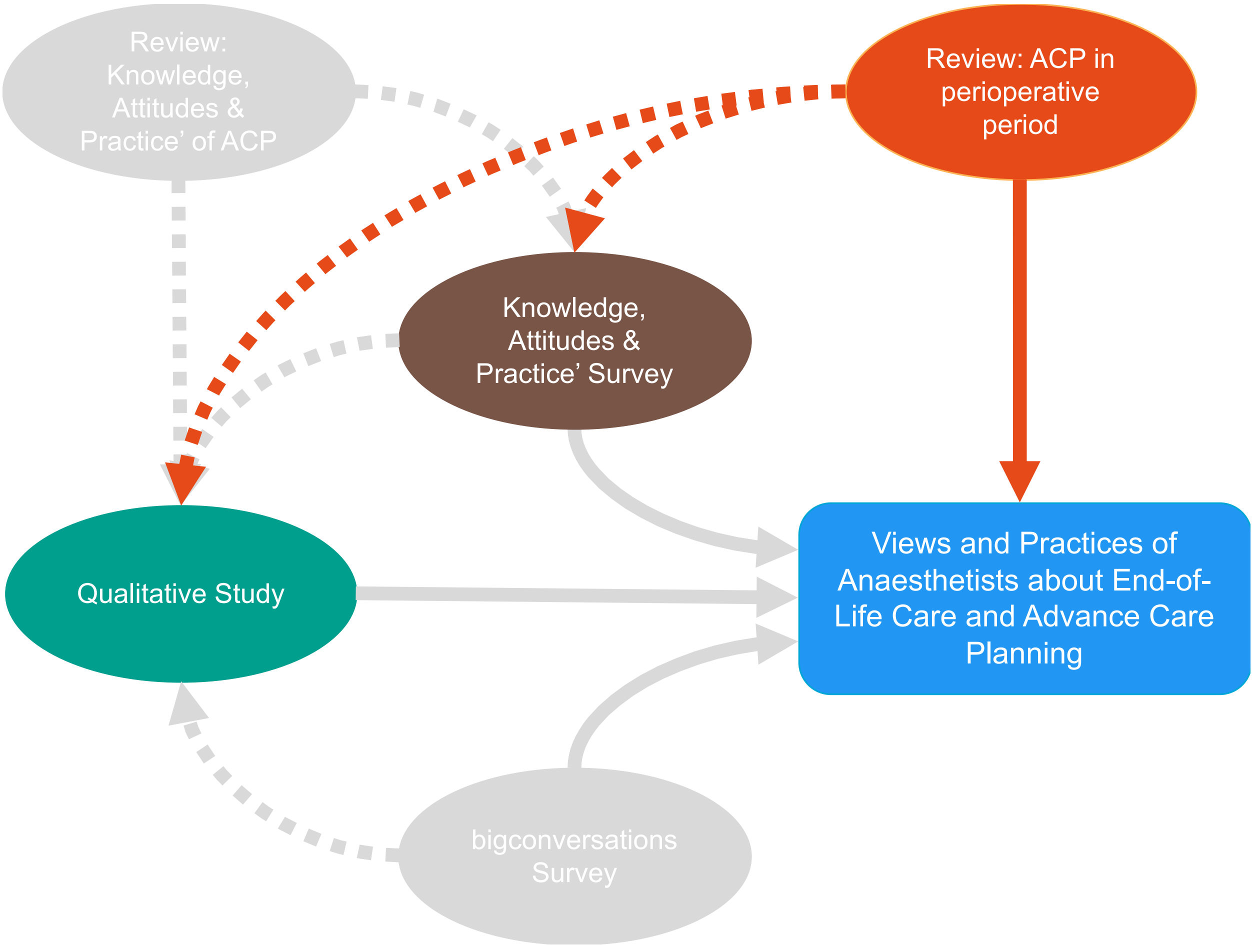
SurveyMonkey (SurveyMonkey Inc., San Mateo, CA, USA) stores European customer data on servers in the United States. Data protection legislation prohibits the transfer of personal data to countries or territories outside the European Economic Area unless the European Commission has determined that there is an *"adequate level of protection"* (219). In respect of the United States the adequacy finding only relates to organisations which are certified members of the EU-US Privacy Shield framework (219) of which SurveyMonkey (SurveyMonkey Inc., San Mateo, CA, USA) is one (220). Additionally, a data processing agreement was in place between SurveyMonkey (SurveyMonkey Inc., San Mateo, CA, USA) and the account holder. Data was then transferred to UCL Data Safe Haven for analysis. The process for anonymisation of the data is outlined in Figure 6.

Figure 6 Process for Anonymisation of Survey Data

2.2.7 Study Team

The work of this thesis has been carried out by me (DB) with oversight from my supervisors CVP, DW and MM. Where a specific task was undertaken by someone other than me this has been documented within the thesis. I have received additional advice from Dr Rachel Taylor (RT) regarding survey methodology and Dr Malachy Columb (MC) in relation to statistical analysis. The work has been supported by the RCoA who have provided access to the RCoA-MEP.

3 Advance Care Planning and End-of-Life Discussions in The Perioperative Period: A Review of Health and Social Care Professionals Knowledge, Attitudes, & Training



3.1 Introduction

A systematic review was conducted using the KAP framework outlined in Section 1.3.6. This review sought to describe the reported knowledge and attitudes of HSCPs towards perioperative ACP and to outline any examples of current practice or barriers to delivery.

This review was designed to highlight gaps in the literature which could then be explored within this thesis. Whilst the focus of this thesis is anaesthetists, this review included studies involving all HSCPs. This was to better inform the methodology of subsequent workstreams. Studies focussing on other HSCPs could highlight widespread misunderstandings, opinions, or barriers which may also be applicable to anaesthetists. Similarly, tools such as survey instruments, educational, or training programmes developed for other HSCPs may be modifiable to explore similar themes with anaesthetists.

3.2 Methods

3.2.1 Design

This was a systematic review of the literature. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement was used to guide the review (221). A review protocol was registered in PROSPERO: registration number CRD42017052595.

3.2.2 Review Questions

The review was guided by the following questions:

I. What is the attitude of HSCPs towards having EoL and ACP conversations with patients in the perioperative setting? How confident are HSCPs in having such conversations?

II. What is the level of knowledge reported by HSCPs involved in perioperative care with regards to having EoL and ACP conversations in the perioperative setting?

III. What are the knowledge and training limitations identified by HSCPs involved in perioperative care with regards to having EoL and ACP conversations in the perioperative setting?

IV. Are there any interventions (i.e. educational programmes) currently being designed or used to train those involved in perioperative care to have EoL / ACP discussions with patients?

3.2.3 Search Strategy

A review of peer-reviewed journal articles using multiple databases was performed between January and February 2017: PubMed; Embase; CINAHL Plus; Web of Science; and ProQuest Central. Additionally, a grey literature search was carried out using the databases OpenGrey and Trip. The Population-Intervention-Comparison-Outcomes-Setting (PICOS) framework (222) was used to develop the search strategy (Table 3). The search used a combination of keywords and subject headings for the concepts of ACP and perioperative medicine where appropriate. An example search strategy can be found in Appendix 1. Results were combined into Mendeley (version 1.17.3; Elsevier; Amsterdam, Netherlands) and duplicates removed. The reference lists of included articles were screened to identify additional relevant publications.

Table 3 PICOS Framework Used in Development of Search Strategy SR-pACP

Population	HSCPs involved in the perioperative care of patients. This will include anaesthetists (anesthesiologists) and surgeons but may also include critical care physicians, orthogeriatricians, or others involved during the perioperative period.
Intervention	The levels of knowledge, attitudes towards, and training of HSCPs regarding ACP and EoL discussions with patient's in the perioperative setting. In particular, how comfortable and confident healthcare professionals are having these conversations.
Comparator	There is no *'control'* group given the nature of this review. It is possible that if educational programs are discovered they may have a comparator group consisting of those not exposed to the educational content.
Outcome	The primary outcome is HSCPs attitudes and knowledge in regard to ACP and EoL conversations in the perioperative period.
	A secondary outcome is to determine if there are any educational / training initiatives to help HSCPs with ACP and EoL discussions and to assess any gaps in education / training.
Setting	The perioperative period.

3.2.4 Study Selection

The articles were screened by me and CVP in three phases (title and article type (DB), abstract (CVP and DB), and full text (CVP and DB) based on the following criteria:

- Focussed on the knowledge, attitudes, or training of HSCPs who have EoL and ACP discussions with patients.
- These conversations were pre-emptive and occurred within the perioperative period.

When there was disagreement CVP and I discussed responses until agreement was reached.

The perioperative period was defined as *'the moment from which the decision to undergo surgery has been taken until the patient has returned to best health and no longer requires specialist input'* (adapted from RCOA document *'Perioperative Medicine: The pathway to better surgical care'* (23)).

The definition of HSCPs was *"individuals who maintain health in humans through the application of the principles of evidence-based medicine and caring"*. This was adapted from a definition previously used by the World Health Organisation (WHO) (20). The HSCPs considered relevant during the perioperative period were:

- Surgeons
- Anaesthetists / anaesthesiologists
- Critical care physicians
- Orthogeriatricians
- Any other involved in the perioperative period

3.2.5 Data Extraction

The included articles were analysed using a data extraction form developed in Excel (version 16; Microsoft Corporation, Redmond, WA, USA). The categories used in the data extraction form are summarised in Appendix 2. The form was developed after the initial screening of full-text articles.

3.2.6 Data Synthesis

Data were exported from the spreadsheet and the main article characteristics were collated. Because of the wide variation in the studies it was not possible to undertake meta-analysis or other statistical techniques. A qualitative approach was used where emergent themes were observed and analysed in relation to the research questions.

3.2.7 Quality Assessment

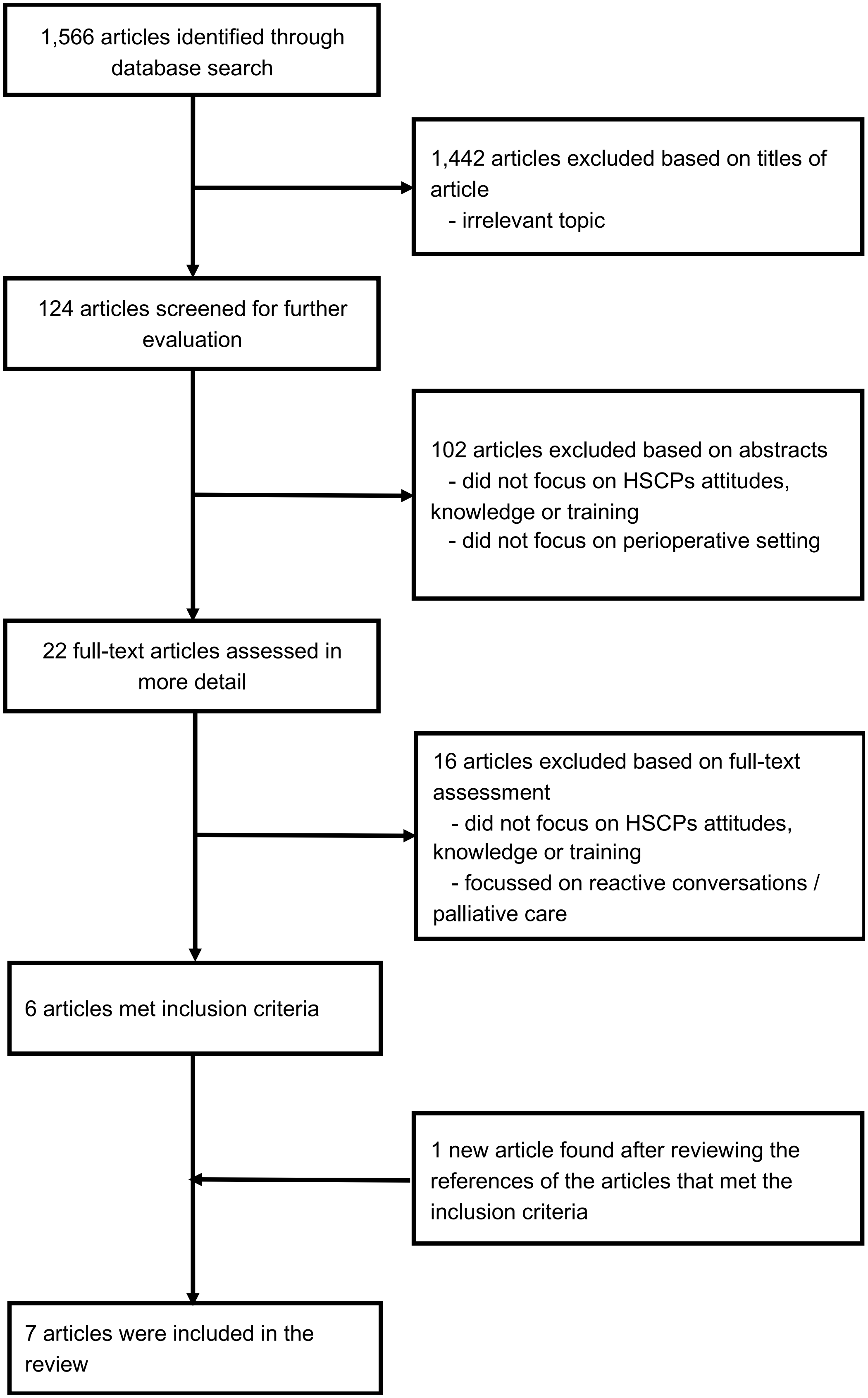
The methodological quality of the studies was critically appraised using the Mixed Methods Appraisal Tool (MMAT) (223–225). CVP and I rated the articles independently. We then discussed responses until agreement was reached and inter-rater reliability was calculated using the kappa statistic (226).

3.3 Results

3.3.1 Identification of Studies

The initial search yielded 1,998 articles (76 from CINAHL, 318 from EMBASE, 297 from ProQuest, 723 from PubMed, 144 from Web of Science, 7 from OpenGrey and 433 from Trip). Once duplicates were removed, there were a total of 1,566 articles. These were screened based on title of article, resulting in 124 (Figure 7). Screening based on abstracts left 22 articles for full text review. Screening of the full texts led to 6 articles meeting the inclusion criteria. Following review of the references of the articles which met the inclusion criteria a further 1 article was included. Thus, the final review included 7 articles.

Figure 7 Study Selection Procedure for Reviewed Articles SR-pACP



No limits to language or date of publication were applied to the search. Articles were not restricted based on the type of study design. Articles were excluded that focussed on reactive discussions (e.g. withdrawal of life sustaining treatment or terminal diagnoses) as opposed to pre-emptive discussions (i.e. prior to a patient's deterioration or having a complication).

3.3.2 Study Characteristics

The characteristics of the seven studies included in the review are presented in Table 5. All articles originated in either the United States (five) or Switzerland (two). Despite searching the grey literature no articles were found which met the inclusion criteria.

The majority of studies had quantitative designs (six) and one was qualitative. The most common quantitative data collection method was a self-administered survey, either online or on paper. One quantitative study used self-scoring and scoring from standardised patients following Objective Structured Clinical Examination (OSCE) scenarios. The qualitative study used semi-structured interviews.

Surgeons or surgical trainees were participants in all of the studies. Other specialists included in some of the studies were: anaesthetists (two), general practitioners (two), physicians (two) and intensivists (two)

Table 5 Description, Including Results, of Articles Included SR-pACP

Authors	Country	Study Design	Population	Data Collection Methods	Knowledge	Attitudes	Identified Educational Gaps & Limitations	MMAT Score
Amini et al. (2014) (227)	USA	Quant.	59 / 125 hepato-biliary surgery fellows	Self-administered online survey	75% rated themselves as well or very well prepared to discuss EoL care decisions with a patient.	19% thought that attending physicians viewed treating the psychosocial needs of patients as a core clinical competency.	56.7% described never being observed having EoL conversations with patients by an attending physician.	***
						12% thought their attending physician viewed ACP as a routine part of care.	63.3% reported never receiving feedback on these conversations.	
Ayres et al. (2015) (228)	USA	Quant.	15 general surgery residents	Paper survey handed out at weekly academic meeting			26.6% agreed or strongly agreed the surgical resident curriculum contains an adequate amount of communication education.	**
							33.3% agreed there was adequate palliative care / EoL care education.	

Bradley et al. (2010) (149)	USA	Qual.	10 physicians caring for high-risk surgical patients including surgeons, anaesthetists and intensivists	Semi-structured interviews		Respondents describe the benefit of ACP: specifically using the presence of an AD as a platform for discussions about the limitations of surgical therapy as well as a way to broach the possibility of limitations of life-supporting therapy postoperatively.		****
						Respondents expressed frustration with the inherent ambiguity of ADs and reported conflict between the drive for surgical cure and the treatment limitations that are intrinsic to ADs.		

						Some felt the ACP discussion should happen with somebody who has a longstanding relationship with the patient i.e. family physician.		

Falcone et al. (2014) (229)	USA	Quant.	27 senior surgery residents	OSCE stations with standardised patients (SPs); self-scoring; and formal scoring by SPs.	Residents self-scored themselves as a mean of 5 on a 7-point Likert scale [4-6 IQR] as to whether they agree with the statement *"I am trained to discuss this issue [goals of care] with patients*".		Authors found that "despite frequently performing difficult communication tasks …, residents are not routinely observed by an attending physician". Only 29% of senior residents said that had received feedback from a staff member.	***
					Residents self-scored themselves as a mean of 2 on a 7-point Likert scale [2-4 IQR] as to whether they agree with the statement *"I feel nervous discussing this issue with patients".*			
					Residents self-scored themselves as a mean of 5 on a 7-point Likert scale [4-6 IQR] as to whether they agree with the statement *"I am skilled at this difficult conversation"*			

Gigon et al. (2015) (Medicine) (230)	Switzerland	Quant.	164 physicians: mix of specialities including GP, Gen. Med., Cardiac, Intensivists	Paper survey mailed to respondents.	Physicians rated themselves as a mean of 8.1 (SD 2.1) / 10 when asked about their quality of communication (1 being poorest and 10 highest quality) to the statement *"To involve the patient in the decisions about the treatments that he/she wants if he/she gets too sick to speak for him/herself*". There was no statistically significant difference between specialties.	In theory 82% of respondents would ask potential cardiovascular patients if they had an AD; 64% would ask for a copy for the medical notes; 51% would ask if it was still accurate.		***
						47% of respondents said they felt it was the GPs responsibility to start ACP conversations; 26% cardiologists; 19% internists; 2% intensivists.		
						No intensivists (0/22) rated their speciality to be the one to initiate ACP conversations; 61% of GPs felt they were best placed; 17% of cardiologists; 35% of internists.		

Gigon et al. (2015) (Minerva Anestesiologica) (231)	Switzerland	Quant.	164 physicians; mix of specialities including GP, Gen. Med., Cardiac, Intensivists	Paper survey mailed to respondents.	14% had never heard of ACP.	85% of physicians felt ACP was useful.	44% of those who said they wouldn't have ACP conversations did so as they felt they had a lack of knowhow.	***
						77% would help a cardiovascular patient write an AD.	43% of physicians felt their information about ADs came from patients / colleagues / friends; post-medical school courses 42%; journals 29%; medical school 13%.	
						62% of those who said they wouldn't have ACP conversations did so as they felt the topic would induce fear in the patient; 47% that it would induce unease.		
						42% felt before major surgery was the optimal time to discuss ACP.		

Hadler et al. (2016) (232)	USA	Quant.	69 anaesthetists and surgeons	Paper survey handed out at joint anaesthesia / surgery education case conference.	92.9% of respondents felt that sometimes or always an elderly patient would undergo surgery without adequate discussion about how surgery and post-op care would impact their QoL.	34% of respondents would confirm whether an AD was in place prior to taking a critically unwell patient to theatre.	10.1% of respondents said they had attended formal informed consent.	***

3.3.3 Quality Assessment

The scores from the quality assessment are presented in Table 5. Only one study covered all of the criteria included in the appraisal tool. Inter-rater agreement was 83%, with a Cohen's kappa of 0.67, which indicates substantial agreement.

3.3.4 HSCPs ACP Knowledge

Five of the articles looked at how physicians appraised themselves in terms of their knowledge of, preparedness for, or ability to have ACP or EoL conversations with patients in the perioperative setting. Three studies (227,229,230) reported self-scoring of HSCPs and all found that individuals rated themselves highly in terms of preparedness and skill in having such discussions. One study (231) found that 14% of respondents had never heard of ACP and that 44% would avoid having ACP conversations due to a lack of knowhow. Another (232) found that 92.9% of respondents felt that elderly patients would often undergo surgery without adequate discussion about how surgery would impact their quality of life.

3.3.5 HSCPs Attitudes Towards ACP

Four studies investigated the attitudes held by HSCPs involved in the perioperative care of patients towards ACP and ADs. Two studies (149,231) reported that physicians felt that ADs were useful, however, for some there was concern that the inherent ambiguity of ADs meant there could be conflict between the drive for surgical cure and the treatment limitations that are intrinsic to ADs (149). There was also concern expressed that the topic could induce fear or unease in patients (231).

One study (227) looking at surgical trainees found that only 19% thought that attending physicians viewed treating the psychosocial needs of patients as a core clinical competency and only 12% thought their attending physician viewed ACP as a routine part of care.

Two studies (149,230) asked which speciality should be having these discussions with patients. There was no consensus although some HSCPs expressed the opinion that it should be someone with a longstanding relationship with the patient (149,230). No intensivists who were asked rated their speciality to be best placed to have such discussions and there was no mention of anaesthesia as the appropriate specialty

(230).

One study (230) asked about the timing of ACP and EoL conversations and found that 42% felt before major surgery was the optimal time to have such discussions.

3.3.6 Training Limitations

Five studies identified educational or training gaps and limitations for HSCPs. Two studies (227,229) found a majority of trainees were never observed having ACP and EoL discussions by an attending physician and never received feedback. Another (228) found that only around one third of respondents felt the surgical curriculum contained sufficient education with regards to communication, EoL, and palliative care issues. Finally, one study (232) found that only 10% of respondents had received formal consent training.

3.3.7 Educational Interventions

One study (229) described a difficult conversation OSCE with standardised patients which was used for both junior and senior surgical residents. The study described performance of candidates in the OSCE and as such did not include validation or evaluation of the OSCE itself. Therefore, it is not possible to comment on its validity or effectiveness.

3.4 Discussion

The most striking finding of this review is the paucity of evidence. Despite having broad search terms and including grey literature only seven articles were found which met the inclusion criteria. None of these articles originated from the UK. There are social, attitudinal, and legal differences between the UK, North America, and Europe meaning it may not be possible to transpose all of these findings to a UK context. It is not clear whether the lack of UK data represents a lack of perioperative ACP or a lack of reporting in the literature. There is currently no standardised data about ACP discussions or AD completion rates in the general population making it difficult to understand their prevalence. Data that are available indicate that uptake can vary significantly by location and by study. A systematic review of US studies found the reported prevalence of AD completion ranged from 0 to 93.8% (233). This review concluded that approximately 1 in 3 US adults have completed some form of AD whilst data from Australia, the UK, and continental Europe suggests completion rates of ~14% (234) and ~4% (27,235) respectively. This would suggest ADs are less established within the UK and Europe and this may be a partial explanation for a lack of UK data.

From the information that was available HSCPs tended to have a positive opinion towards ACP when asked. However, it was believed that this view was not always shared with their colleagues and, in particular, by senior surgeons (227,229). The possible reasons for this have been described in Section 1.3.4.

Family practitioners were cited as being best placed to lead such discussions given their long-standing relationship with the patient however this relationship is not universal. Additionally, they may lack the necessary knowledge of surgery and critical illness to make this an effective discussion about the associated risks and potential outcomes. This review has demonstrated an absence of anaesthesia and ICM being considered as leading specialties in the delivery of ACP, both by their own practitioners, and other specialties.

Although not unanimous this review identified that HSCPs tend to rate themselves highly in terms of their knowledge and preparedness to engage with ACP. The studies which reported a high degree of knowledge were mostly conducted on trainee doctors and this may reflect a greater emphasis on communication in the medical curriculum in recent years (236). All of these studies relied on the inherent bias of self-scoring and thus may not accurately capture true knowledge levels. As most studies focused on trainee doctors, the self-scoring may be unreliable as trainees, by definition, lack the expertise and experience of more senior clinicians. Nonetheless, the one study which included an OSCE scenario using simulated patients did demonstrate a high level of successful patient conversations alongside self-reporting of good knowledge. Despite the high levels of knowledge and supportiveness reported, one study (232) found that 92% of respondents thought elderly patients would often undergo surgery without adequate discussion about its potential impact. This finding is discouraging as it implies that despite HSCPs reporting support and adequate knowledge and skills to perform perioperative ACP it is apparently absent from routine clinical practice.

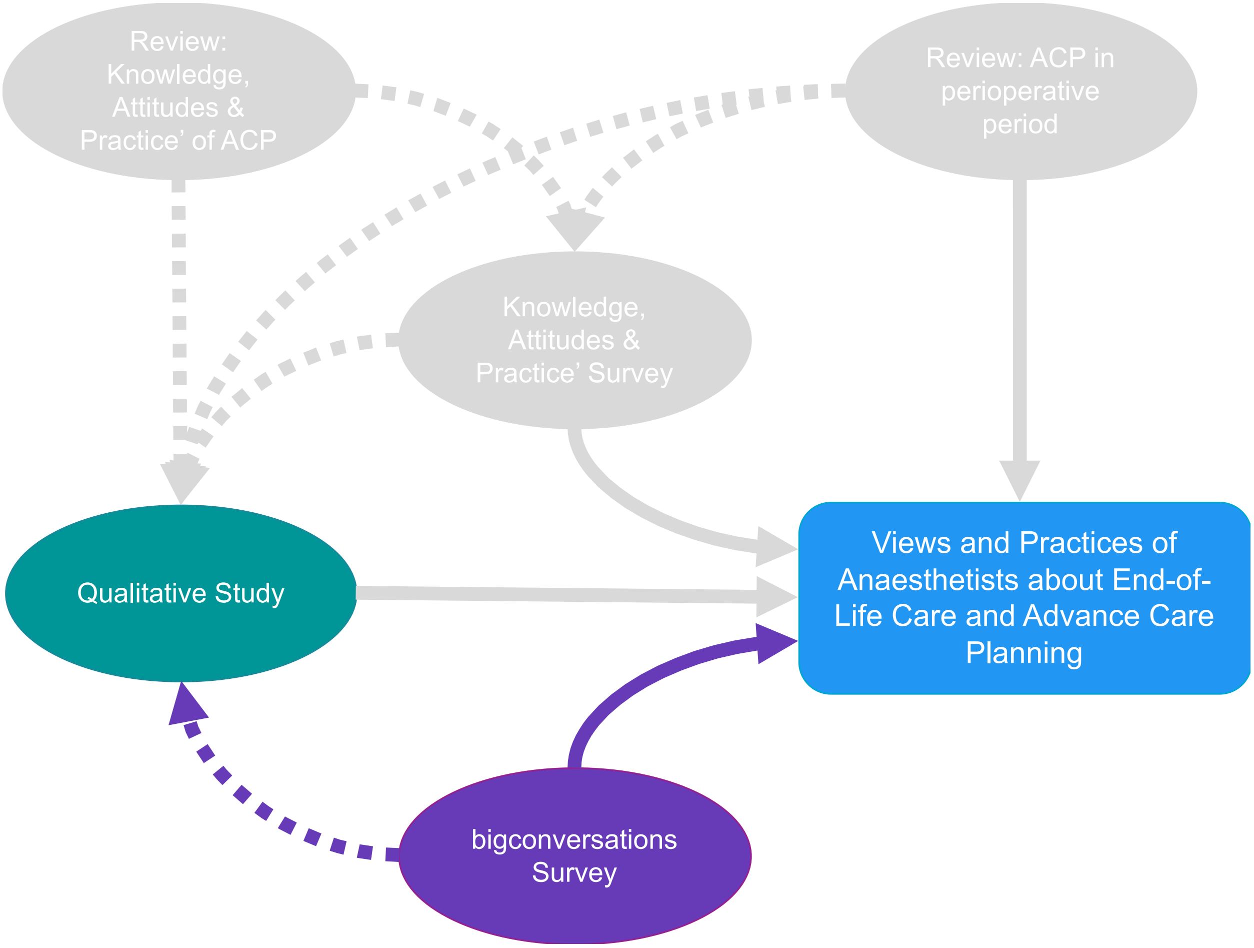
3.4.1 Limitations

This review should be interpreted with its limitations in mind. The literature search was carried out in January and February 2017, so any articles published after this date are not included. Additionally, although multiple broad search terms were used it is possible that articles were missed that did not use these terms. This was evident by the fact that an additional article was found during the review of references. The review included studies of multiple designs and methodologies making it difficult to draw overall conclusions. The quality assessment found that the studies were of variable quality with only one covering all of the criteria covered by the MMAT appraisal tool. Five of the articles were survey based. A common limitation in survey research is sampling bias, where respondents who take part in the survey are only those who have some interest in the subject, which may lead to skewed results. One of the aims of the review was to capture interventions in the form of educational programmes being used to provide training on having EoL or ACP discussions with patients. Most educational programmes are not published in peer-reviewed journals. This was accounted for by inclusion of grey literature in a manner similar to other reviews of education for HSCPs (237). Despite this some educational programmes may still have been missed.

3.5 Conclusion

The most striking finding of this review was a lack of information about ACP in the perioperative setting. The evidence that was available indicated that HSCPs have a mostly positive view of the concept of ACP and EoL discussion in the perioperative period, but, that there is little training or educational content available. Despite this, most HSCPs report feeling well equipped to have such discussions. There was no evidence of ACP becoming a routine part of training or practice in the care of patients in the lead up to high-risk surgery.

4 bigconversations: A National Survey of Anaesthetists' Preferences for their Own End of Life Care



4.1 Introduction

The BC workstream was designed to describe the most important components of EoL and ACP discussions. It involved the development of a validated questionnaire which could be used to describe individual views, wishes, and preferences for EoL care. Following this, the questionnaire was used to describe the views of UK anaesthetists. It was designed in a manner which allowed new issues to be raised by respondents which had not been previously considered by myself or others.

Section 1.2.4 highlighted some broad direction for ACP discussions provided by UK institutions. These provide general targets but do not detail what is considered most important at EoL. Systematic reviews exploring the concept of a *'good death'* have highlighted some recurring key themes: life completion / feeling of closure; treatment preferences; clear decision making; control of pain and symptoms; dignity / being seen and perceived as a person; and family (238,239). Survey research has found that the majority of members of the public report that they would prefer quality over quantity of life (240,241) and that avoiding inappropriately prolonging death is a key component of good EoL care (242,243). Members of the public also report wanting to avoid dying in hospital with a home death most heavily favoured (240,244–248). HSCPs similarly report that they would choose to avoid high-intensity treatments should they be terminally unwell in studies from North America (144,249–257), Europe (258), and Asia (259).

When directly compared, HSCPs are less likely to choose high-intensity medical treatments for themselves (255,258) or their relatives (259) than members of the public. One study comparing medical students at different stages of training found that after two years of training students reached similar rates of refusal of *'aggressive'* treatments as practicing doctors (251). This would suggest a *'dose effect'* where increasing understanding and knowledge of treatment options results in a decreasing preference for high-intensity treatments at EoL.

In the UK, anaesthetists have a large role in the delivery of high-intensity treatments such as cardiopulmonary resuscitation (CPR), inotropic support, renal replacement therapy (RRT), and mechanical ventilation. ICM as a speciality continues to draw most heavily on the anaesthetic workforce with the majority of ICM doctors also being anaesthetists (260). This experience gives them an important insight into the realities of high-intensity treatments. The views of anaesthetists towards their own EoL care will provide an important perspective which should help inform patients and HSCPs undertaking ACP discussions.

4.2 Methods

4.2.1 Study Design

Currently there are no commonly used reporting guidelines for survey research although multiple checklists have been described and/or used in the literature (186,188–190,261–265). Bennett et al. (187) reviewed the availability of guidance for reporting survey research from major journals as well as reviewing published studies on the quality of survey reporting. They identified 33 items as critical to reporting survey research. In combination with other checklists reported in the literature (186–190,261–265) this was used to create a framework for both the design and reporting of this workstream (Appendix 3).

4.2.2 Description of Questionnaire

The study used a modified questionnaire (Appendix 4) comprised of two sections. The first measured respondents' EoL preferences. The second collected demographic information as well as respondent permissions for future contact.

The first section is comprised of ten questions. The first eight questions follow a set format where respondents are given a statement, e.g. *"As my healthcare team treat me, I would like …",* followed by two opposing preferences, e.g. *"my healthcare team to do what they think is best"* versus *"I want to have a say in every decision"*, at each end of a 5-point Likert scale. Respondents then select the position on the scale which best reflects their opinion. Q9 is a multiple-choice question. Q10 is an open-ended free-text question.

The second section has ten questions collecting respondents' demographic information and two questions asking for permission to be contacted with results and about future work. For those who agreed to future contact they were also asked to provide an email address.

4.2.3 Development of Questionnaire

The questionnaire is an adaption of the *'Serious Illness Conversation Guide'* provided by The Conversation Project (104). The *'Serious Illness Conversation Guide'* was produced to guide individuals in how to think about and then have a conversation about their EoL wishes. The Conversation Project is a US organisation which is dedicated to helping people talk about their wishes for EoL care. It works in collaboration with the Institute for Healthcare Improvement and is part of Ariadne Labs, a centre of Brigham and Women's Hospital and the Harvard T.H. Chan School of Public Health. Permission was sought, and granted, from Ariadne Labs for its modification and use.

The unaltered document was piloted with a group of anaesthetists (n=37) at a central London teaching hospital and a consultation process about its usability took place. The outcome was that the document needed to be shortened in order to capture the attention of people for whom this may not be an immediate concern. A Cochrane review has previously demonstrated that shorter questionnaires result in greater response rates (266) and this view was confirmed by the consultation process. A modified questionnaire was produced consisting of ten questions. All but one open-ended questions were removed as they were commonly ignored by the pilot group and were said to take too long to complete. Again, this is consistent with previous research which shows that doctors, and the public, are less likely to complete open as opposed to closed-ended questions (266,267). The modified instrument was transferred to an online platform. This was in contradiction with evidence which suggests that online questionnaires typically result in a lower response rate than those mailed (268,269). However, the benefits in terms of cost, ease of data collection and analysis, and the fact that up-to-date address details are difficult to access were felt to outweigh the expected slight decrease in response rate.

4.2.4 Validity

Survey research can be defined as the use of quantitative, or numerical, data to describe trends, attitudes, or opinions (178). It is a form of measurement, which in its broadest conception is the *“assignment of numbers to objects or events according to rules”* (270). A difficulty for social research is that often the concepts under investigation are too abstract to be considered either objects *(“things that can be seen or touched”)* or events (*“results, consequences or outcomes”)* (270,271). Measurement in the social science can be seen most usefully as an attempt to link these abstract concepts with some form of empirical gauge and to do so in a way which is explicit, organised, and allows for classification (271).

In this context error can be viewed as the gap between an, often numerical, indicator e.g. an answer to a survey question, and the underlying, intangible, concept, e.g. EoL wishes, which is the real interest of the researcher (271). When this error is small, analysis of indicators can lead to useful inferences about the underlying concepts. When the relationship between indicator and the concept is weak, one can make incorrect and misleading inferences and conclusions (271). In classical test theory the result of any measurement is viewed as a combination of these two factors: the *true* score and the error, or gap, between indicator and concept (272). Errors are commonly grouped into either random error ('noise') or systematic errors ('bias') (272). Random error is inversely related to the measurements' reliability, whilst systematic error is traditionally assessed as part of validity (271).

A valid questionnaire is therefore one which measures what it intends to (262). There are four types of validity which can be assessed in questionnaires (Table 6 (189,273)).

Table 6 Description of Types of Validity

Method	**Description**
Face validity	A subjective measure which involves asking whether on the surface a questionnaire looks like it measures what it claims to.
Content validity	An evaluation, usually by subject experts, about whether a questionnaire accurately assesses all fundamental aspects of the topic.
Criterion validity	The correlation of a questionnaire with some form of previously approved gold standard measurement.
Construct validity	The degree with which a questionnaire adequately assesses a hypothetical construct e.g. in medicine this may be a disease such as schizophrenia which is a constellation of symptoms.

In this case face validity had already been established as the questionnaire was an adaption of a well-regarded and referenced tool, the *'Serious Illness Conversation Guide'* (274). This document has won numerous awards and has been downloaded more than 300,000 times hence, in my view, this adequately met the requirements of face validity. Despite face validity having already been established I believed it necessary to provide additional rigor by also ascertaining the questionnaire's content validity.

Criterion validity was not possible to calculate as no *'gold standard measurement'* exists to measure EoL wishes and preferences. Similarly, EoL wishes are not a well-defined hypothetical *'construct'* so it was not possible to measure construct validity.

4.2.4.1 Content Validity for bigconversations Questionnaire

In order to quantify the content validity of the questionnaire the content validity index (CVI) was used as recommended by Polit et al. (275).

Multiple iterations of content validity were utilised. The first iteration involved an 11-member expert panel. 12 experts were chosen using the criteria outlined in Box 3. and asked to participate (276). 11 agreed to take part which exceeded the minimum of 8 recommended for the process to be valid by Polit et al. (275).

Box 3 Criteria for Appointment to Expert Panel for Content Validity BC

- Clinical experience with EoL decision making
- Professional certification in related area
- Presented professional papers on related topic in regional / national / international professional meetings
- Published papers on related topic in regional / national / international journals
- Personal interest / experience of EoL decisions

The composition of the panel is detailed in Box 4.

Box 4 Composition of Expert Panel for Content Validity BC

- Palliative Care Physicians (n = 2)
- Critical Care & Anaesthesia Physician (n = 2) (one was also a medico-legal expert)
- General Practitioner (n = 1)
- Professor of Nursing (n = 1)
- Emergency Department & Critical Care Physician (n = 1)
- Research Scientist with background in survey development (n = 2)
- Lay Members (n = 2)

The expert panel were asked to comment on three domains as recommended by Grant & Davis (277):

- relevance of each question
    - and suggestions for revisions
- clarity and wording of each question
    - and suggestions for revision
- comprehensiveness of the entire questionnaire
    - and suggestions of any additional areas felt to be inadequately covered

This process was conducted using an online form generated in SurveyMonkey (SurveyMonkey Inc., San Mateo, CA, USA). This allowed experts from across the country to take part at a time and place which was suitable for them.

4.2.4.1.1 Relevance

To determine relevance, Individual-Content Validity Index (I-CVI) values were calculated and used to guide revision or removal of questions.

To calculate an I-CVI value for relevance experts were asked to rate the relevance of each question on a 4-point scale (Table 7) (276).

Table 7 Scoring System for Calculation of I-CVI

Rating	**Description**
1	not relevant
2	somewhat relevant
3	quite relevant
4	highly relevant

For each question, the I-CVI value is computed as the number of experts giving a 3 or 4 rating divided by the total number of experts.

Any question with an I-CVI value <0.78 was to be considered a candidate for revision and those with an I-CVI value significantly below were to be considered for removal (275).

The Scale-Content Validity Index (S-CVI) value was calculated using the S-CVI/Ave method whereby the average I-CVI value is calculated across all questions. In order to be judged as having excellent content validity the S-CVI value should be >0.9 (275).

The results are presented in Table 8. Eight questions had an I-CVI value of 1 indicating that all experts agreed that these questions were *quite* or *highly* relevant. Two questions had an I-CVI value of 0.82. In both cases 2 experts felt these questions were only *somewhat* relevant. All questions met the threshold of >0.78 and the S-CVI was calculated at 0.96

Table 8 Content Validity Index Values BC

Question	Not Relevant	Somewhat Relevant	Quite Relevant	Highly Relevant	I-CVI
Q1. I would like to know …	0	0	2	9	1.00
Q2. As my healthcare team treat me I would like …	0	0	2	9	1.00
Q3. If I had an illness from which I were going to die, I would want to …	0	2	1	8	0.82
Q4. If I had an illness from which I were going to die, I would want medical treatments aimed at prolonging my life for …	0	0	3	8	1.00
Q5. If I had an illness from which I were going to die, I would …	0	0	3	8	1.00
Q6. If I had an illness from which I were going to die, and I disagreed with my family and/or friends about my medical treatment I would …	0	0	5	6	1.00
Q7. In the final period of time before I die, I would ...	0	0	2	9	1.00
Q8. When it comes to sharing information, I want my family and / or friends to know ...	0	2	6	3	0.82
Q9. If I were able to choose where to die I would prefer to be in ...	0	0	4	7	1.00
Q10. The three most important things …	0	0	3	8	1.00
				S-CVI	0.96

4.2.4.1.2 Clarity

Experts were asked whether each question was well written, unbiased, and at an appropriate reading level for members of the public. The results are presented in Table 9. With the exception of Q1, it was felt that the clarity of the questions could be improved.

Table 9 Clarity of Questionnaire BC

Question	**Yes**	**No**
Q1. I would like to know …	11	0
Q2. As my healthcare team treat me I would like …	10	1
Q3. If I had an illness from which I were going to die, I would want to …	7	4
Q4. If I had an illness from which I were going to die, I would want medical treatments aimed at prolonging my life for …	5	6
Q5. If I had an illness from which I were going to die, I would …	4	7
Q6. If I had an illness from which I were going to die, and I disagreed with my family and/or friends about my medical treatment I would …	4	7
Q7. In the final period of time before I die, I would ...	8	3
Q8. When it comes to sharing information, I want my family and / or friends to know ...	6	5
Q9. If I were able to choose where to die I would prefer to be in ...	9	2
Q10. The three most important things …	9	2

Experts were then asked to provide comments and examples of changes to the wording of questions. These comments were collated and used to modify the questions. These modified questions were then reviewed by the expert panel in an iterative process until agreement was reached. The original and modified questions are presented in Table 10 with alterations highlighted in bold.

Table 10 Original and Modified Questions BC

	Original Question	**Modified Question**
Q1.	As a patient I'd like to know... only the basics OR all the details about my condition / treatment	As a patient I would like to know... only the basics **about my condition / treatment** OR all the details about my condition / treatment
Q2.	As my doctors treat me I would like my doctors to do what they think is best OR to have a say in every decision	As my **healthcare team** treat me I would like... my **healthcare team** to do what they think is best OR **I want** to have a say in every decision
Q3.	If I had a terminal illness I would prefer to … to not know how quickly it is progressing OR know my doctors best guess for how long I have to live	If I had an illness **from which I was going to die** I would want to … **know how long my healthcare team think I have left to live** OR **not know how long I have to live**

Q4.	How long do you want to receive medical care? Indefinitely, no matter how uncomfortable treatments are OR Quality of life is more important to me than quantity	**If I had an illness from which I was going to die, I would want medical treatments aimed at prolonging my life for …** **as long as possible, even if my quality of life was poor OR** **only as long as I have a good quality of life**
Q5.	What are your concerns about treatment? I'm worried that I won't get enough care OR I'm worried that I will get overly aggressive care	**If I had an illness from which I was going to die, I would …** **want all medical treatments no matter how uncomfortable they may be OR** **not want medical treatments that may prolong my life but could cause discomfort**
Q6.	What are your preferences about where you want to be? I wouldn't mind spending my last days in hospital OR I want to spend my last days at home	**If I was able to choose where to die I would prefer to be in a ...** **hospital OR** **home / normal place of residence OR** **hospice OR** **other (Please specify)**
Q7.	How involved do you want your loved ones to be? I want my loved ones to do exactly what I say, even if it makes them a little uncomfortable OR I want my loved ones to do what brings them peace, even if it goes against what I've said	**If I had an illness from which I was going to die and I disagreed with my family and/or friends about my medical treatment I would…** want my **family / friends** to do exactly what I say, even if it makes them a little uncomfortable OR want my **family/friends** to do what brings them peace, even if it goes against what I've said
Q8.	When it comes to your privacy, when the time comes to, I want to be alone vs. I want to be surrounded by my loved ones.	**In the final period of time before I die, I would...** **like to be left quietly by myself as much as possible** OR **like my family and friends to spend as much time with me and be with me when I die**
Q9.	When it comes to sharing information, I don't want my loved ones to know everything about my health vs. I am comfortable with those close to me knowing everything about my health.	When it comes to sharing information, I want my **family and/or friends** to know ... **nothing about my health and how my illness is progressing** OR everything about my health **and how my illness is progressing**
Q10.	What do you feel are the three most important things that you want your friends, family and/or doctors to understand about your wishes and preferences for end of life care?	What do you feel are the three most important things that you want your friends, family and/or **healthcare team** to understand about your wishes and preferences for end of life care?

4.2.4.1.3 Comprehensiveness

The expert panel was asked to judge the comprehensiveness of the questionnaire. Following review of the questionnaire experts were asked *"Does this questionnaire cover the most important aspects of end of life care for an individual?"*. Experts unanimously agreed that the questionnaire was comprehensive.

4.2.5 Demographic Questions

The expert panel were also asked which demographic questions should be asked of participants. Relevant questions were felt to be gender, age, ethnicity, occupation, religion, health status, and caring responsibilities. The terminology for these questions was that used by the Office for National Statistics (ONS) for the 2011 national census (278). Where new guidance was available (279) the question terminology was updated to incorporate this.

4.2.6 Sample Selection

4.2.6.1 Sampling Frame

The sampling frame was the RCoA-MEP which aims to represent the diversity of grades, ages, gender, and geographic distribution of anaesthetists in the UK. Members of the RCoA-MEP agree to be contacted about survey research and provide their contact details to allow for this. At the time of the survey it was comprised of 1,913 members.

4.2.6.2 Representativeness of Sample

The RCoA-MEP is a self-selecting group who have agreed to take part in survey research in order to better inform the RCoA. It is to be expected that this group is more engaged and proactive than others, however, there is no reason why their views on EoL care would be different from their colleagues. The benefits of expected higher response rates and usable contact details were felt to outweigh the limitations described.

It was not known, but unexpected, that there would be a high level of variation in answers between different demographic groups. Stratifying the population into sub-populations would also have required a much larger sample size than could reasonably be expected. Given this it was not felt appropriate to stratify the population into sub-populations and the population was considered homogenous.

4.2.6.3 Sample Size

Given that the response rate was unknown and that there was no disadvantage in terms of cost or time, as this was an electronic survey, the entire sampling frame was surveyed.

Although the entire sampling frame was surveyed a sample size calculation was performed in advance to discover the minimum number of respondents required to give the desired level of precision.

The sample size for the survey was calculated using Cochran's formula for sampling for proportions (280).

<u>Formula 1 Cochran's Formula for Sampling Proportions</u>

$$n_0 = \frac{t^2 \, x \, p \, x \, q}{d^2}$$

n_0 = sample size
t = the value of the t-distribution corresponding to the chosen alpha level
p = estimate of the proportion of the population who will give a certain answer
q = 1-p
d = margin of error expressed as a proportion

For this survey the alpha level was set at 0.05 i.e. there is a 5% risk that the true margin of error exceeds the acceptable margin of error. This level is generally accepted as appropriate for most research (281). Given this, with reference to a t-distribution table as the population to be studied exceeds 120, t = 1.96 (282).

The accepted margin of error has been set at 5%, which is widely considered acceptable for categorical data (281,283). This means that the proportion of the population who would answer X is within +/-5% of the proportion calculated from the research sample.

Cochran's formula for sampling proportions, as opposed to for continuous data, was chosen as although Likert scales are ordinal, and are occasionally treated as continuous, when the data is reported it is done so as categorical. Taking Q1 as an example:

I would like to know...

1	*2*	*3*	*4*	*5*
only the basics about my condition / treatment				*all the details about my condition / treatment*

Although it would be possible to calculate the mean score it would be essentially meaningless. Instead, treating the scale as categorical data and being able to present the data as proportions i.e. X% (+/-5%) *'wanted to know only the basics'* provides much more interesting and usable information.

The final component in determining the sample size is the variance within a population. Cochran (280) suggests four ways to incorporate variance estimates

- take the sample in two steps and use results from the first step to work out the number of extra responses required
- use pilot study results to estimate the variance
- use data from similar studies on the same or a similar population
- use an estimate

When estimating the variance of a proportionate variable Krejcie and Morgan (283) recommend using 0.5 as this produces the maximal variance and the largest and most conservative estimate of sample size.

Using Cochran's (280) formula the sample size for the survey was calculated as 384.

For finite populations Cochran (280) pointed out that a smaller sample size can be used, given that the sample will make up a greater proportion of a small population than a large one.

Formula 2 Cochran's Formula for Sampling Proportions in a Finite Population

$$n = \frac{n_0}{1 + (\frac{n_0 - 1}{N})}$$

n_0 = the sample size calculated by first formula (in this instance 384)	
N = the population size (in this instance 15,000)	

Thus, a sample size of 375 was required in order to provide a level of precision of +/-5% with a 95% chance that the true population value lies within this margin of error.

4.2.7 Survey Administration

The questionnaire was administered using the online survey platform SurveyMonkey (SurveyMonkey Inc., San Mateo, CA, USA). Members of the RCoA-MEP were initially contacted via an email from the RCoA inviting participation. The survey introduction page acted as a consent form and participant information sheet.

The survey was open from 7/1/19 until 31/1/19 with two reminders sent to those who had not taken part on the 15/1/19 and 21/1/19. This is in keeping with evidence suggesting that surveys attempting two follow-ups show significantly greater response rates than either no follow-up or three or more attempts (269).

4.2.7.1 Strategies to Increase Response Rate

Surveys of HSCPs generally, and doctors in particular, are characterised by low, and falling, response rates (269). The decision of whether or not to respond to a survey is typically taken in the first 24-48 hours with most potential respondents making a decision immediately based on quick impressions (284).

Strategies to increase response rate in surveys generally fall into two categories: incentive based (financial or non-financial) and design based approaches (285).

Financial incentives have been shown to increase participation in both the general population and specifically for physicians (266,269,285). A small $1 pre-paid incentive appears to be the most cost-effective approach with decreasing returns when the incentive is increased beyond this (285). Non-financial incentives e.g. pens, stickers, sweets etc. have not been shown to not have an impact on physician response rate (269,285). Despite this no incentives were offered to those who took part. Partly, this was related to cost and logistics. Even a relatively small pre-paid incentive, e.g. £1, would have had a significant cost given that our required sample size was 375 and a low response rate would have increased this significantly. Additionally, creating the infrastructure to deliver a financial incentive online would have been challenging. Another dilemma was the concern that, even modest, financial incentives can be considered *'coercive'*. Singer et al. argue that financial incentives should only be considered *'coercive'* if they are *'unduly'* influential, i.e. they induce participants to undertake risks that they would not have been willing to take had it not been for the financial incentive (286). By this definition I do not believe a small financial incentive could have been considered *'coercive'* however the cost and logistics of providing such a pre-paid incentive were prohibitive.

Design based approaches include the use of personalised mailings, questionnaire wording, and sponsorship (285). Dillman et al. (284) provide various design recommendations which aim to maximise response rate (Table 11). These utilise the concept of *'social exchange'*: this is simply the idea that people are more likely to comply with a request if they have the general expectation that the benefits of doing so will eventually outweigh the costs (284). It is distinct from economic exchange as the benefits are not specified in advance but are based on trust, reciprocity, and altruism (284). Systematic reviews (266,285) and meta-analysis (269) have also been published which aim to provide quantitative evidence supporting or refuting these strategies (Table 11).

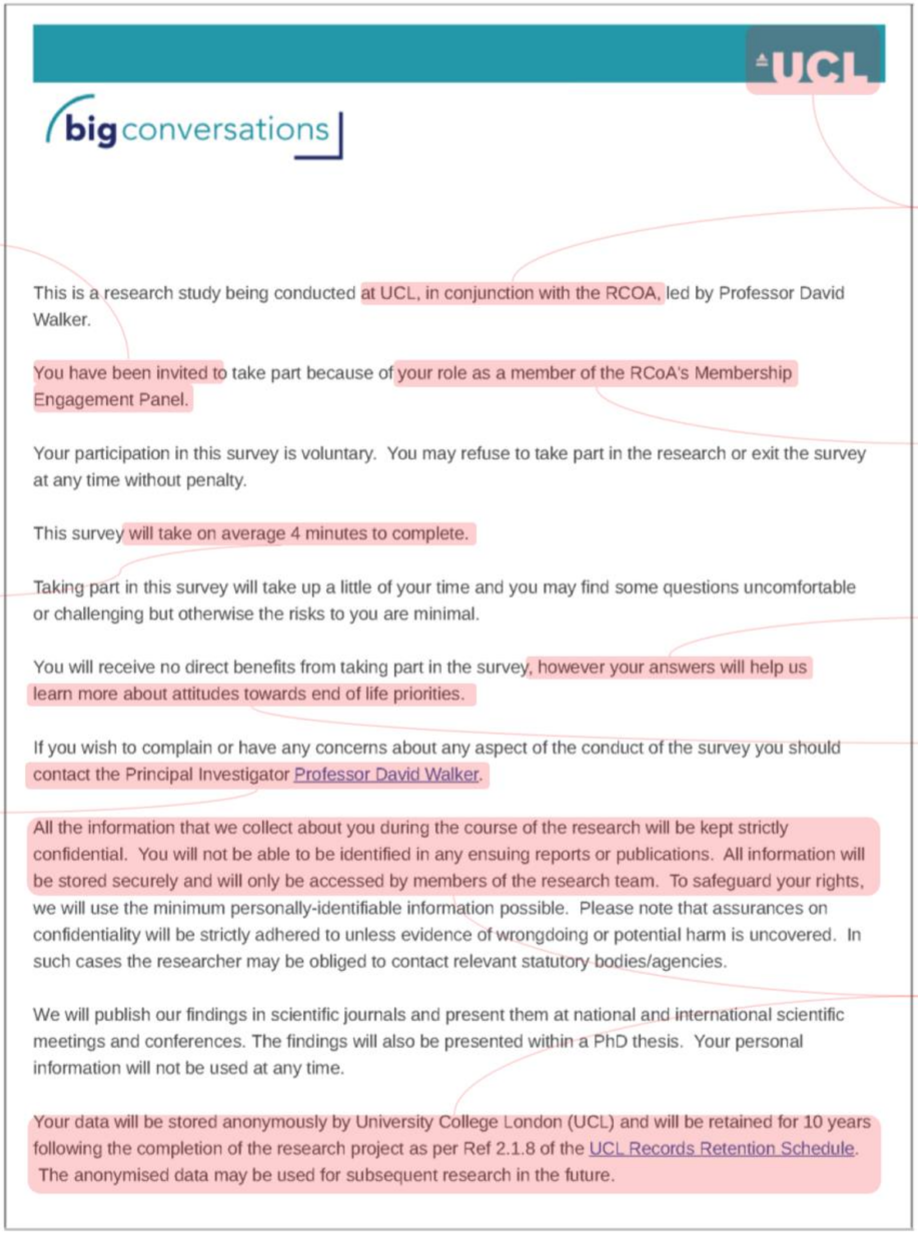
Table 11 Strategies to Improve Survey Response Rates and Supporting Evidence

Using a personalised greeting on the covering letter / questionnaire. - Edwards et al. and VanGeest et al. found that this increased response rates in the general public and amongst physicians (266,285).
Specify how survey results will be used. - Many people feel a significant benefit when contributing to something which benefits others. These actions are particularly satisfying when the beneficiaries are people or groups to which the individual knows or belongs (284). - Edwards et al. found no evidence of increased response rates when benefits to either the participant, sponsor, or society were stressed (266).
Ask for help or advice. - People often feel good when asked for help or advice, especially when only they are able to provide it. Asking for help or advice conveys value to their contribution or opinion (284). - Edwards et al. found no evidence of increased response rates when an appeal or pleading factor was present (266).
Provide a time-estimate - The estimated time for completion provides an estimate of the work that might be required by the potential participant (287). - Edwards et al. found no evidence of increased response rates when providing a time-estimate (266).
Sponsorship of legitimate organisation - Support of a government or professional organisation confers legitimacy and promotes trust. When the organisation has a positive relationship with its members it can provide a sense of reward for the respondent (284). - Edwards et al. showed sponsorship by a university increased response rates for mailed but not for electronic surveys (266).
Convey that others have responded. - Much of human behaviour is motivated by a desire to behave in a manner which is consistent with others (284). - Edwards et al. did find increased response rates when providing a statement that others have responded (266).
Show similarity to other requests an individual has agreed to - People like to feel consistent in their attitudes, beliefs, and actions. As such, people who have committed themselves to a particular role may be more likely to complete tasks which are consistent with this (284).
Establish trust. - Respondents need to be confident that their information will be kept safe (284). - Sponsorship from a legitimate organisation confers this as does a willingness to identify oneself and be contactable (284). - Edwards et al. found assurances about confidentiality led to increased response rate (266).
Provide a deadline - Edwards et al. showed the use of deadlines led to increased response rates for electronic but not postal surveys (266).

The invitation email highlighted that the study was being conducted by the RCoA in conjunction with UCL so as to maximise trust. It was personally addressed. The email was sent from an RCoA email address to reinforce its legitimacy and build upon the previously established relationship between members of the RCOA-MEP and the RCoA. Potential respondents were informed that the survey only took ~4 minutes on average to complete. This was done to both minimise the apparent cost, i.e. time, but also to infer that others had already responded.

The survey introduction sheet acted as a consent form and participant information sheet. It had to meet the requirements of the UCL ethics committee and of the recently implemented GDPR legislation. Within these constraints it was designed using the strategies outlined above to try and maximise response (Figure 8).

Figure 8 Questionnaire Introduction BC



This is a research study being conducted at UCL, in conjunction with the RCOA, led by Professor David Walker.

You have been invited to take part because of your role as a member of the RCoA's Membership Engagement Panel.

Your participation in this survey is voluntary. You may refuse to take part in the research or exit the survey at any time without penalty.

This survey will take on average 4 minutes to complete.

Taking part in this survey will take up a little of your time and you may find some questions uncomfortable or challenging but otherwise the risks to you are minimal.

You will receive no direct benefits from taking part in the survey, however your answers will help us learn more about attitudes towards end of life priorities.

If you wish to complain or have any concerns about any aspect of the conduct of the survey you should contact the Principal Investigator Professor David Walker.

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. All information will be stored securely and will only be accessed by members of the research team. To safeguard your rights, we will use the minimum personally-identifiable information possible. Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the researcher may be obliged to contact relevant statutory bodies/agencies.

We will publish our findings in scientific journals and present them at national and international scientific meetings and conferences. The findings will also be presented within a PhD thesis. Your personal information will not be used at any time.

Your data will be stored anonymously by University College London (UCL) and will be retained for 10 years following the completion of the research project as per Ref 2.1.8 of the UCL Records Retention Schedule. The anonymised data may be used for subsequent research in the future.

Invitation as opposed to requirement or demand

Emphasis of support from 'legitimate' organisations

Reminder of acquiescence to previous requests

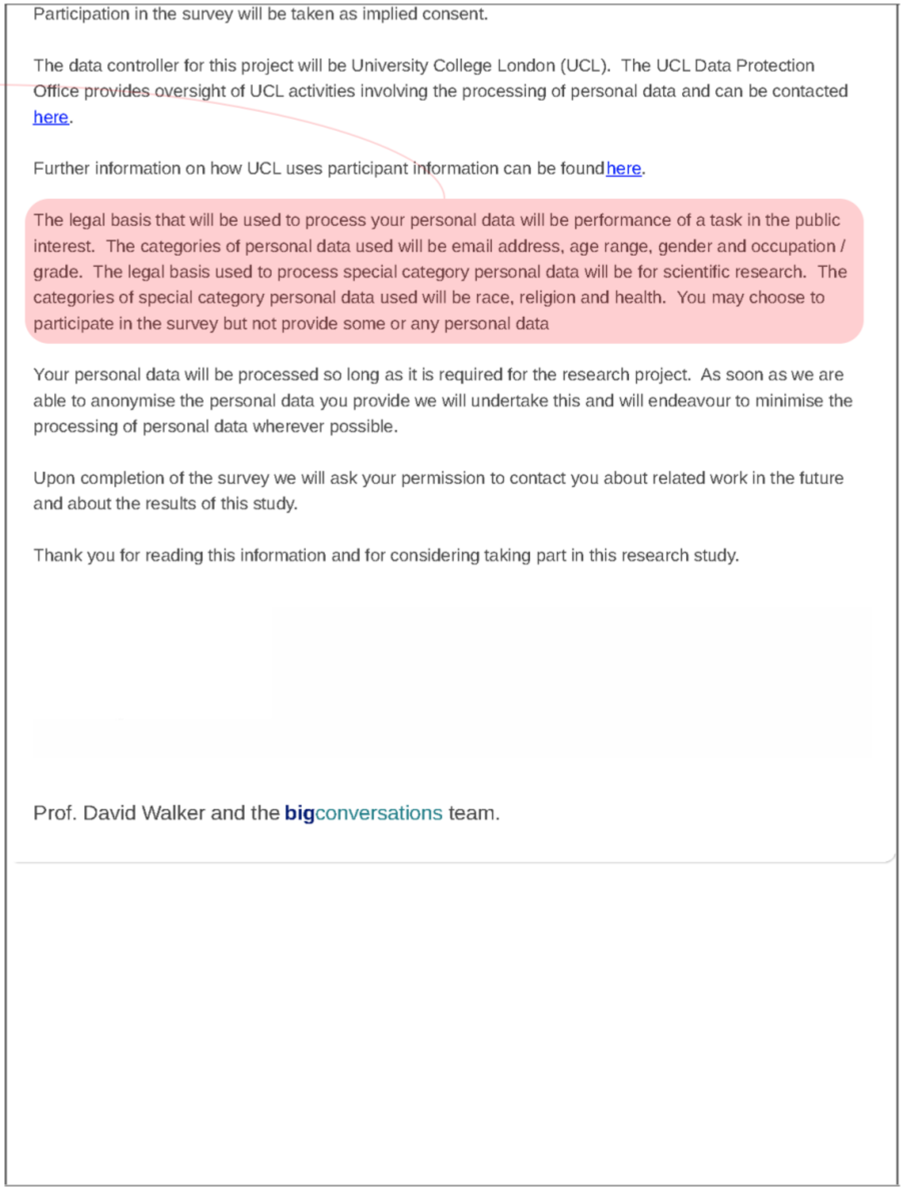
Minimising time commitment and creating the impression that others have already responded

Request for help

Emphasis of benefits to others

Name and contact details easily available

Emphasis on anonymity, confidentiality and data security


Requirement of GDPR

Participation in the survey will be taken as implied consent.

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data and can be contacted here.

Further information on how UCL uses participant information can be found here.

The legal basis that will be used to process your personal data will be performance of a task in the public interest. The categories of personal data used will be email address, age range, gender and occupation / grade. The legal basis used to process special category personal data will be for scientific research. The categories of special category personal data used will be race, religion and health. You may choose to participate in the survey but not provide some or any personal data

Your personal data will be processed so long as it is required for the research project. As soon as we are able to anonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

Upon completion of the survey we will ask your permission to contact you about related work in the future and about the results of this study.

Thank you for reading this information and for considering taking part in this research study.

Prof. David Walker and the **big**conversations team.

4.2.8 Analysis of Non-Response Error

Non-response bias occurs if there are systematic differences between respondents and non-respondents, meaning that conclusions drawn from the respondent subsample may not generalise to the entire sample and by extension to the target population (288). The error that non-participation introduces is particularly difficult to determine because researchers rarely have information about non-respondents (289).

Response rate is frequently used as a proxy for determining the quality of a survey under the assumption that a high response rate reduces the likelihood, and impact, of any non-response bias (290,291). This is overly simplistic as a high response rate on its own cannot identify whether there is a difference between respondents and non-respondents, how severe the difference is, or in which direction it occurs. Indeed, even surveys with a response rate >80% have been shown to suffer significant non-response bias (292). Regardless, maximising response rate is normally the first approach to minimising non-response bias (288) and the strategies used to achieve this are discussed above (Section 4.2.7).

Various approaches to assessing non-response bias have been described. The most common is to check for similarities between respondents and known population characteristics (288,290,293). Limited data about population characteristics were available from the RCoA's Medical Workforce Census Report from 2015 (215) and these were used for comparison.

An alternative approach is to use a process called wave analysis which compares early and late responders (294). This is based on the idea of a *'continuum of resistance'* (289). This is an assumption that late respondents are *'almost'* non-respondents given that had data collection ceased earlier they would have been classed as non-responders (294). Thus, we can compare late respondents with others in the survey to assess potential differences which may approximate non-response bias (295). This was assessed non-parametrically using Kruskal-Wallis one-way and Cuzick trend analyses. A Bonferroni corrected alpha level was calculated as <0.00625. Q9 was assessed using Fisher's exact test as data was categorical and both Kruskal-Wallis and Cuzick trend analyses require ordinal data.

4.2.9 Incomplete Submissions / Missing Data

A commonly used tactic to avoid *'missing data'* from online questionnaires is to employ *'forced answering'* where respondents are unable to proceed through the questionnaire without providing an answer for every question (296). The advantage of this approach is that it minimises, or avoids altogether, non-response to questions, which is often naively used as an indicator of data quality (297). Concerns have been raised that *'forced answering'* is unethical as it coerces respondents to answer even if they wish not to. Additionally, forced answering may result in poorer quality data as respondents likely have a good reason for choosing not to give an answer (e.g. not understanding the question; no appropriate category; unwillingness to disclose personal information) (284). The coerced answer may not accurately reflect the respondent's views, or, in some circumstances the coercion itself may change the views of the respondent. This phenomenon is known as *reactance*, which occurs when an individual's freedom or choice is threatened or removed. The individual may then view the imposed alternatives less favourably than they would otherwise have done, and view as more attractive the denied alternative (298).

For these reasons respondents were not forced to answer any questions and could skip or leave blank if they so wished. The number of non-respondents for each question is presented with the results.

4.2.10 Reliability

Reliability is concerned with error in measurement (272). In classical test theory a portion of the variability in participants' test scores will be due to a genuine underlying difference. This is the true score. The remaining variance is composed of random measurement error. Thus test score is equal to true score plus error (300).

There are generally considered three possible sources of measurement error within the classical framework: stability across time, inter-rater error, and content sampling of items (301). Measurement of the first two of these are relatively intuitive. Comparison of results from a retest after an interval, using an identical test, indicates how stable scores are (302). Comparison of results between two, or more, raters measuring the same subject(s) illustrates inter-rater error (303). Content sampling refers to the idea that a questionnaire is made up of a random sample of all possible questions that could be present. The questionnaire is a combination of multiple questions all measuring a single construct e.g. EoL preferences. Therefore, the questions should be highly interrelated because they all measure the same thing. This relationship between questions is called '*internal consistency'*. If there is a strong relationship between questions it is assumed that the construct has been measured with a high degree of consistency and is reliable (301).

The reliability coefficient is the ratio of variance between subjects to the total variability:

$$reliability = \frac{subject\ variability}{subject\ variability + measurement\ error}$$ (304–306)

As the total variability is always greater it produces a number between 0 and 1 (304). When all variability is the result of subject variability the reliability = 1, whilst when all variability is the result of measurement error (and there is no subject variability) reliability will = 0 (272).

An important corollary of this is that reliability is not only the measurement of agreement (304). It is a comparison of variability between subjects to total variability meaning that if there is no variability between subjects then reliability will be 0 even if there is perfect agreement (304). Reliability reflects how well a questionnaire is able to differentiate between subjects. Therefore, when there is relative homogeneity between subjects the reliability of a questionnaire may decrease as it is more difficult to differentiate between subjects (304). Another consequence of this is that the reliability of a questionnaire is linked to the population in which it is being tested. One cannot refer to the reliability of a questionnaire, only the reliability of the results obtained from using the questionnaire in a specific population (304).

For this survey a test-retest approach was taken to measure the stability of results over time. The questionnaire measures multiple different aspects of EoL decision making and it would be inappropriate to sum the questions to create a single score. As such it is not possible to calculate internal consistency.

The most common way to estimate the reliability coefficient for quantitative ratings is to use a form of intraclass correlation (305). For binary or categorical ratings kappa coefficients are the norm (305). The answers from the first eight questions are best described as ordered categories and are treated as ordinal as recommended by

Kraemer (306). This is important as many statistical tests which assess categorical data ignore the *'order'* (306). For *'ordered categorical'* data it has been recommended that weighted kappa is used to assess reliability (307,308). When a quadratic weighting scale (weights are calculated as the square of the discrepancy) is used the result is identical to that of the intraclass correlation coefficient (304,309).

Alongside the calculation of kappa, the median absolute differences are presented (including 99.4% CL) to show the magnitude of the difference between test and retest responses. Additionally, the 90% intervals of agreement are presented for the absolute differences between test and retest scores. The 90% intervals of agreement show the maximum number of categories difference for 90% of respondents.

4.2.10.1 Kappa

Cohen's kappa was first described in 1960 (310) and is a coefficient which measures the level of agreement between two raters. It adjusts for the fact that agreement can arise through true agreement between raters but may also be the result of chance. It can be described as the *'proportion of agreement after chance agreement has been removed from consideration'* (310).

Formula 3 Cohen's Kappa

$$\kappa = \frac{\rho_0 - \rho_e}{1 - \rho_e}$$

$\boldsymbol{\kappa}$ = kappa coefficient

ρ_0= proportion in which there was agreement between raters

ρ_e= proportion in which agreement is expected by chance

The original kappa coefficient reduces the data to agree/disagree meaning if a respondent answered a question with a 5 on the initial test and 4 on the retest this would be treated the same as answering 5 and then 1. Clearly, the first example, representing a small change, indicates a more reliable instrument than the second, showing a completely opposing opinion. With weighted kappa (311) the level of agreement varies and depends on the discrepancies between answers. Weighted kappa was used in this case. The R package 'irr' was used to calculate kappa (312).

4.2.10.1.1 Sample Size Calculation for Kappa

There are currently no gold standard methods to precisely calculate sample size for determining kappa when there are >2 categories. The R package KappaSize (313) was used in a manner similar to that described by Hollands et al. (314). A sample size was estimated for each question using the following parameters: an alpha value of 0.05; power of 0.80; using 2 raters; the proportion of answers in each category was predicted using pilot study results; a null hypothesis of a kappa of 0.4 (the boundary which is commonly cited as representing moderate to fair agreement (226)); and, an expected kappa of 0.6 (the boundary which is commonly cited as moderate to substantial agreement (226)). The calculated required sample sizes are presented in Table 12. The highest sample size calculated was for Q1. 131 was therefore taken as the minimum sample size required for calculating test-retest reliability.

Table 12 Sample Size Calculations for Determining Reliability BC

Question	Proportions from pilot (n=37)					Standard Deviation from pilot (n=37)	Kappa Sample Size
Q1. I would like to know …	0.05	0.05	0.05	0.15	0.70	0.81	139
Q2. As my healthcare team treat me I would like …	0.05	0.05	0.20	0.35	0.35	1.01	93
Q3. If I had an illness from which I were going to die, I would want to …	0.05	0.05	0.05	0.25	0.6	1.06	120
Q4. If I had an illness from which I were going to die, I would want medical treatments aimed at prolonging my life for …	0.05	0.05	0.10	0.25	0.55	0.75	108
Q5. If I had an illness from which I were going to die, I would …	0.05	0.10	0.25	0.25	0.35	1.16	87
Q6. If I had an illness from which I were going to die, and I disagreed with my family and/or friends about my medical treatment I would …	0.20	0.25	0.25	0.20	0.10	1.23	79
Q7. In the final period of time before I die, I would ...	0.05	0.05	0.10	0.25	0.55	1.02	108
Q8. When it comes to sharing information, I want my family and / or friends to know ...	0.05	0.10	0.05	0.20	0.6	1.10	114
Q9. If I were able to choose where to die I would prefer to be in ...*	-	-	-	-	-	-	-
* This question was modified post-piloting meaning results could not be used to calculate a sample size.							

4.2.10.2 Median Difference Between Test-Retest Scores

The differences between respondents' test and retest score for each question were calculated. If the respondent gave the same answer on both occasions the difference would be 0. If the respondent gave a different answer, then the difference would be between 1 and 4 depending on whether the difference reflected a small or large change. The median of these differences was then calculated. Confidence limits were calculated by application of the binomial distribution (315). Confidence limits were calculated at 99.4% as per the Bonferroni correction for multiple comparisons.

4.2.10.2.1 Sample Size Calculation for Median Difference

The R package pwr (316) was used to calculate power analysis for a one sample t-test. The null hypothesis was set at 0 i.e. the median of the differences in scores between test and retest would be 0, and the alternative hypothesis at 0.5 i.e. the median of differences in scores between test and retest would be at least +/-0.5. An estimate of variance was unavailable from the pilot as test-retest data was not collected. The highest level of inter-respondent variance was for Q6 and this has been substituted into the power analysis. Given that this is the largest estimate of inter-respondent variance, and that a reasonable assumption would be that intra-respondent variance will be lower, this will provide the most conservative estimate for sample size. An alpha value of 0.05 and power of 0.8 was set. The calculated required sample size was 96.

4.2.10.3 Intervals of Agreement

Intervals of agreement were determined by ordering respondent values for absolute difference and calculating the difference between the value at 5% and the value at 95%. Thus, the interval represents the maximum difference for 90% of respondents.

4.2.11 Data Analysis

Data were exported from SurveyMonkey (SurveyMonkey Inc., San Mateo, CA, USA) and uploaded to UCL Data Safe Haven. The analysis was conducted using the R Statistical Computing language (R version 3.5.0; R Foundation for Statistical Computing, Vienna, Austria).

4.2.12 Analysis of Free Text Answers

Free text answers were compiled in a single list and were left unedited (no corrections for spelling or grammar). Data were analysed using thematic analysis (299) to allow for the identification of patterns across the data set. A broadly descriptive type of thematic analysis was employed when developing the themes. Data were read numerous times to ensure immersion with initial notes of potentially interesting aspects made. Following from this the entire dataset was coded. Codes were derived from the data capturing descriptive elements e.g. *"I don't want to be in pain"* was coded *"pain free"*. A review of the coding of the dataset, including the codes used, was performed by CVP and the dataset was then reread and recoded with codes added, modified, or removed as required to ensure the dataset was coded consistently. Potential themes were identified with relevant data collected under each theme and reread to ensure the themes identified appropriately captured the views and beliefs of respondents.

4.3 Results

The invitation to take part was sent to the 1,913 members of the RCoA membership panel by email and 760 (40%) completed the questionnaire.

60% of those who responded were male and the vast majority (95%) were between the ages of 25-64. Half of respondents worked solely within anaesthesia, whilst the others had a range of roles including ICM; pain medicine; perioperative medicine; medicine; emergency medicine; or a combination of these. Consultants accounted for 60% of the sample. Most (96%) described their health to be *'good'* or *'very good'* and were not limited in their day-to-day activities (91%). 21% had caring responsibilities for others because of ill health or disability. 56% were white and 41% identified as Christian whilst 37.4% held no religion. Table 13 presents an overview of the demographic and personal characteristics of respondents.

Table 13 Demographic and Professional Profile of Respondents BC

	n = 760
What is your sex?	
Male	461 (60.9%)
Female	296 (39.1%)
No Answer	3
What is your age?	
0-24	11 (1.5%)
25-44	384 (50.7%)
45-64	336 (44.4%)
65-74	19 (2.5%)
75+	7 (0.9%)
No Answer	3
Are you currently practicing in the UK?	
Yes	688 (90.8%)
No	70 (9.2%)
No Answer	2
In what specialty (specialties) do you work?	
Anaesthesia	385 (50.7%)
Anaesthesia & Intensive Care Medicine	166 (21.9%)
Anaesthesia, Intensive Care Medicine & Perioperative Medicine	44 (5.8%)
Anaesthesia & Perioperative Medicine	40 (5.3%)
Other	37 (4.9%)
Intensive Care Medicine	33 (4.3%)
Anaesthesia & Pain Medicine	21 (2.8%)
Anaesthesia, Intensive Care Medicine, Perioperative Medicine & Pain Medicine	14 (1.8%)
Pain Medicine	6 (0.8%)
Anaesthesia & Other	5 (0.7%)
Anaesthesia, Intensive Care Medicine & Pain Medicine	4 (0.5%)
Intensive Care Medicine & Perioperative Medicine	2 (0.3%)
Perioperative Medicine & Pain Medicine	1 (0.1%)
Perioperative Medicine	1 (0.1%)
No Answer	1
What grade is your current post?	
Consultant	457 (60.6%)
Trainee	224 (29.7%)
Specialty and Associate Specialist (SAS)	54 (7.2%)
Other	19 (2.5%)
No Answer	6
How is your health in general?	
Very Good	453 (59.6%)
Good	278 (36.6%)
Fair	27 (3.6%)
Bad	2 (0.3%)

Are your day-to-day activities limited because of a health problem or disability which as lasted, or is expected to last, at least 12 months?	
Yes, limited a lot	5 (0.7%)
Yes, limited a little	61 (8.0%)
No	693 (91.3%)
No Answer	1
Do you look after, or give any help or support to family members, friends, neighbours or others because of either; long term physical or mental ill-health / disability or problems related to old age?	
No	602 (79.2%)
Yes, 1-19 hours per week	145 (19.1%)
Yes, 20-49 hours per week	9 (1.2%)
Yes, 50 or more hours per week	4 (0.5%)
What is your ethnic group?	
White - Scottish / English / Welsh / Northern Irish / British	428 (56.4%)
Asian / Asian British - Indian	117 (15.4%)
White - Any other white background	62 (8.2%)
Other	26 (3.4%)
White – Irish	21 (2.8%)
Asian / Asian British - Chinese	18 (2.4%)
Asian / Asian British - Any other Asian background	17 (2.2%)
Asian / Asian British - Pakistani	14 (1.8%)
Arab	13 (1.7%)
Black / African / Caribbean / Black British - African	12 (1.6%)
Mixed - Multiple ethnic groups - White & Asian	9 (1.2%)
Mixed - Multiple ethnic groups - Any other mixed / Multiple ethnic background	8 (1.1%)
Black / African / Caribbean / Black British - Caribbean	6 (0.8%)
Mixed - Multiple ethnic groups - White & Black African	4 (0.5%)
Mixed - Multiple ethnic groups - White & Black Caribbean	3 (0.4%)
Asian / Asian British - Bangladeshi	1 (0.1%)
No Answer	1
What is your religion?	
Christian	315 (41.6%)
No Religion	284 (37.5%)
Hindu	86 (11.4%)
Muslim	38 (5.0%)
Other	16 (2.1%)
Buddhist	13 (1.7%)
Jewish	4 (0.5%)
Sikh	1 (0.1%)
No Answer	3

4.3.1 Non-Response Error

The 2015 RCoA's Medical Workforce Census Report estimates that around 68% identify as male compared to 61% (95% CI 57-64%) of respondents. It also estimates that around 53% are Consultants compared to 60% (95% CI 57-64%) of respondents.

Respondents were divided into three *waves* to allow for wave analysis: early responders (n = 485), middle responders (n = 285), and late responders (n = 33). This was determined by whether they responded to the initial invitation (7/1/19) or one of the subsequent reminders (15/1/19 and 21/1/19). No statistically significant difference was detected between the waves at the Bonferroni corrected alpha level. Only Q6 had an uncorrected *P* value <0.05 for both the Kruskal-Wallis and Cuzick trend analyses. These results are presented in Table 14. Based on these results there is no evidence that there was a difference between early, middle, and late responders.

Table 14 Comparison Between Waves BC

Question	**p value for Kruskal-Wallis analysis**	**p value for Cuzick trend analysis**
Q1. I would like to know …	0.81	0.84
Q2. As my healthcare team treat me I would like …	0.54	0.44
Q3. If I had an illness from which I were going to die, I would want to …	0.93	0.73
Q4. If I had an illness from which I were going to die, I would want medical treatments aimed at prolonging my life for …	0.11	0.87
Q5. If I had an illness from which I were going to die, I would …	0.54	0.97
Q6. If I had an illness from which I were going to die, and I disagreed with my family and/or friends about my medical treatment I would …	0.03	0.04
Q7. In the final period of time before I die, I would ...	0.82	0.56
Q8. When it comes to sharing information, I want my family and / or friends to know ...	0.39	0.20
Q9. If I were able to choose where to die I would prefer to be in ...	0.18*	

* calculated using Fisher's exact test as categorical data

4.3.2 Reliability

All those who agreed to be contacted about future work (n = 534) were sent an invitation to retake the questionnaire on 7/3/19. This was 6 weeks following the closure of the original survey. 198 people completed the retest questionnaire which was greater than the minimum calculated sample size required to perform the analysis (Section 4.2.10.1.1) and so no further reminders were sent.

One question had substantial, seven moderate, and one a fair level of agreement when assessed using weighted Kappa (Table 15). The strength of agreement for a given kappa value was determined using Landis & Koch's framework (Table 16) (226). The median size of any change between test and retest scores was at most one out of five categories even at the 99.4%CL. The 90% intervals of agreement showed that 90% of respondents' responses differed by no more than 2 categories. These are presented in Table 15.

Table 15 Test-Retest Reliability BC

Question	**Kappa**	**Strength of Agreement**	**Median Absolute Difference (99.4% CL)**	**90% Intervals of Agreement**
Q1. I would like to know …	0.313	Fair	0 (0 to 0)	2
Q2. As my healthcare team treat me I would like …	0.581	Moderate	0 (0 to 1)	2
Q3. If I had an illness from which I were going to die, I would want to …	0.487	Moderate	0 (0 to 0)	2
Q4. If I had an illness from which I were going to die, I would want medical treatments aimed at prolonging my life for …	0.492	Moderate	0 (0 to 0)	2
Q5. If I had an illness from which I were going to die, I would …	0.496	Moderate	1 (1 to 1)	2
Q6. If I had an illness from which I were going to die, and I disagreed with my family and/or friends about my medical treatment I would …	0.631	Substantial	0 (0 to 1)	2
Q7. In the final period of time before I die, I would ...	0.592	Moderate	0 (0 to 1)	2
Q8. When it comes to sharing information, I want my family and / or friends to know ...	0.519	Moderate	0 (0 to 1)	2

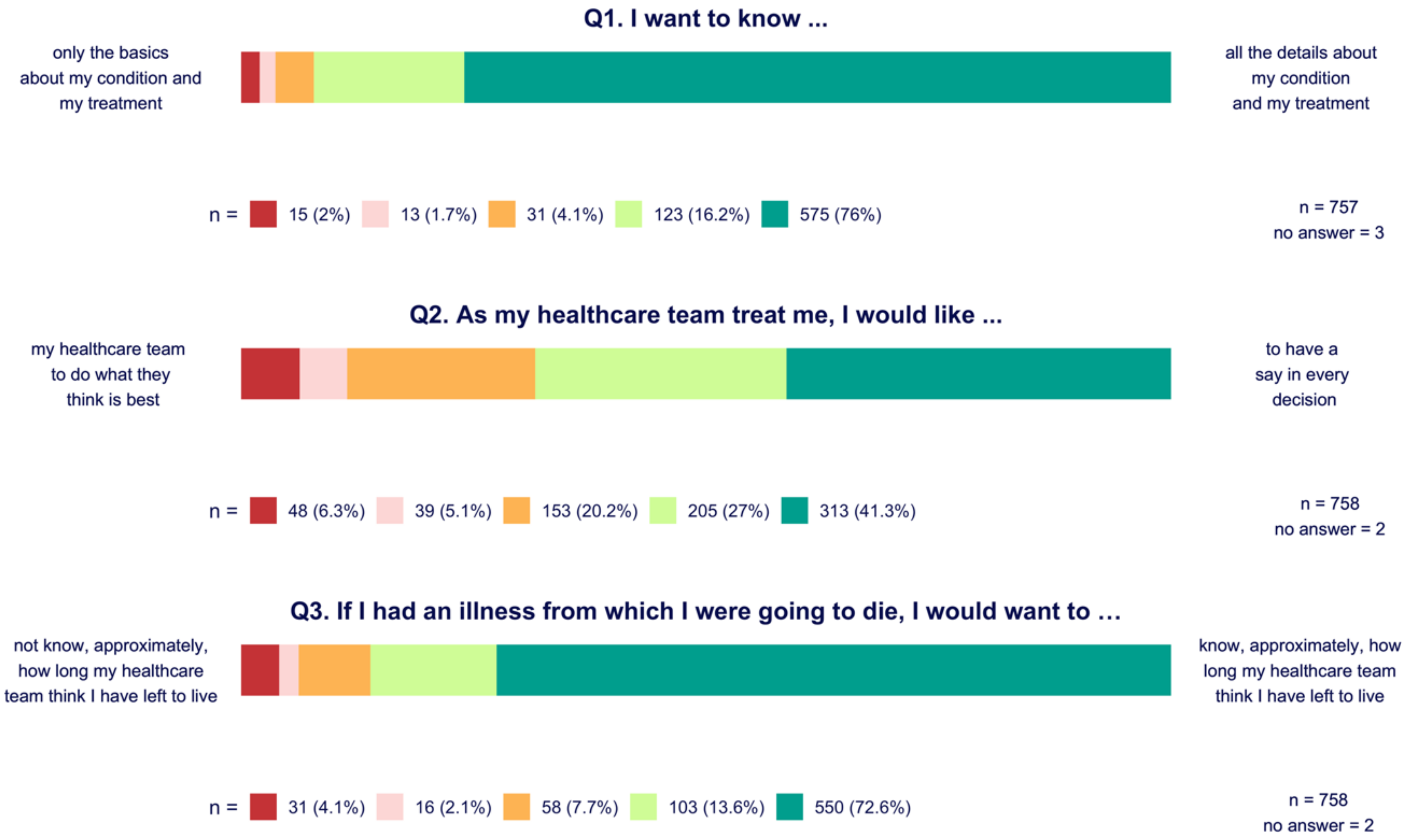
Table 16 Landis & Koch's Agreement Measures for Categorical Variables

Kappa Statistic	**Strength of Agreement**
<0.0	Poor
0.0 – 0.2	Slight
0.21 – 0.4	Fair
0.41 – 0.6	Moderate
0.61 – 0.8	Substantial
0.81 – 1	Almost Perfect

4.3.3 Patient Engagement

The level of *‘patient engagement’* was measured in Q1, Q2, and Q3 (Figure 9) with most respondents favouring a high level of input. 92% of respondents wished to be well informed about their condition and prognosis and 68% wanted to be heavily involved in decision making about their health.

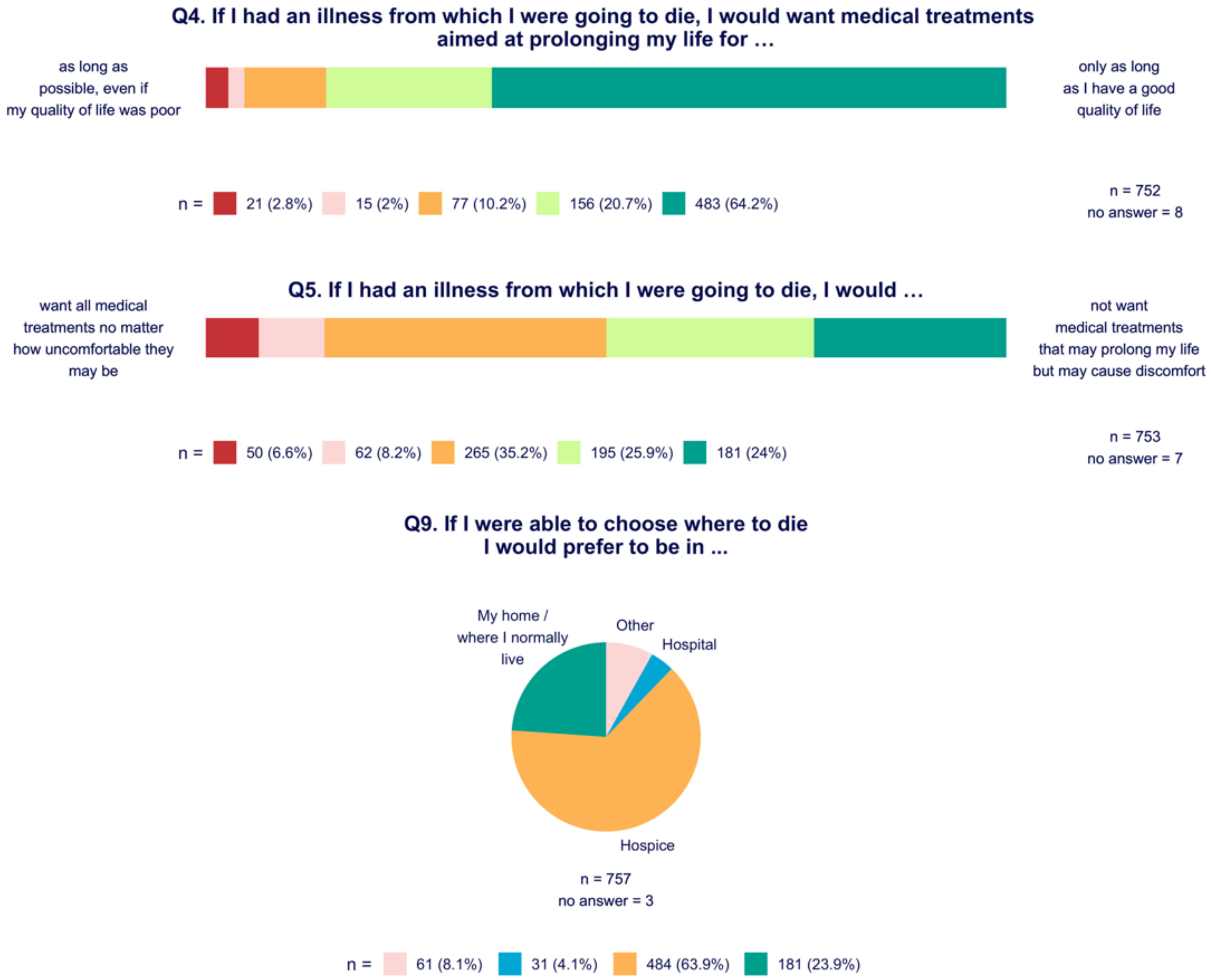
Figure 9 Level of Patient Engagement (Q1, Q2, Q3)



4.3.4 Intensity of Treatment

The intensity of treatment at EoL was explored in Q4, Q5, and Q9 (Figure 10). Most respondents (84%) would choose to forego treatment aimed at prolonging life should that life be of poor quality and many (49%) would avoid treatments which may prolong life at the expense of discomfort. A wish to avoid the *'medicalisation'* of death was reflected in Q9 where the desire of most respondents (91%) was to avoid hospital as a place to die.

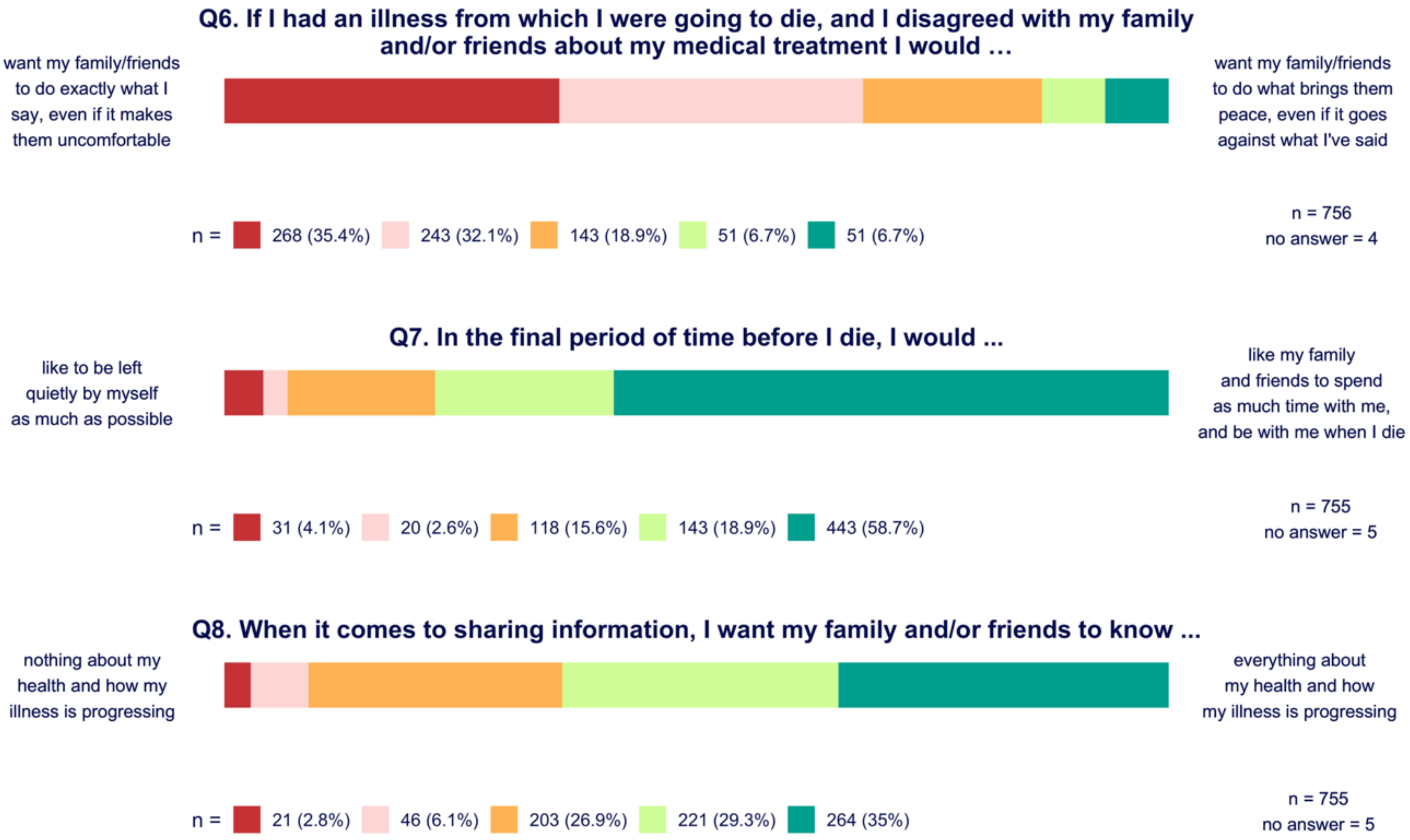
Figure 10 Intensity of Treatment (Q4, Q5, Q9)



4.3.5 Role of Family and Friends

The role desired of family and friends was explored in Q6, Q7, and Q8 (Figure 3). Q6 revealed that most (67%) would still wish for family and friends to follow their wishes regarding medical treatments even if it made them uncomfortable. Most (64%) would be happy to share information about their health and illness with family and friends.

Figure 11 The Role of Family and Friends (Q6, Q7, Q8)



4.3.6 Free Text Answers

When answering the qualitative free-text question 688 respondents provided at least one useable answer, 664 provided two, and 612 provided three. This resulted in a total of 1,964 free text answers available for analysis. The main themes which emerged are summarised in Table 17. Three key themes are described in depth. Some responses did not fall neatly into any of these three themes; however, these themes did cover >1,900 of the 1,964 pieces of data.

The three themes will be discussed in depth but in order to frame this discussion it is useful to place them into a chronology. I have modified a model described in the Neuberger report (25) and divided dying into three phases. The first is the period of diagnosis of a life limiting illness or recognition of increased risk of dying. This has been termed the *'end of life phase'*. The second is the period of acute deterioration including the days and hours leading up to death, the *'dying phase'*. Last is the period following death, *'after death'*. A particularly important focus for respondents was the transition between the *'end of life phase'* and the *'dying phase'* and at what point an individual would accept moving from one to the next.

4.3.6.1 Decision Making

The decisions to be taken, who should make them, and what would influence them were the most prominent consideration of respondents. Many declared a desire to maintain autonomy for as long as possible. For instance, one respondent wrote *"as long as I am able to make decisions, the decisions are mine and I want you to respect them and support me"*. For some a feeling of control was important: *"I like to be in control",* and there was a demand for decisions to be respected even after the loss of capacity: *"ensure that my decisions are implemented"*. This sometimes included the refusal, or request, for specific medical treatments: *"I do not want to be NG/PEG fed"* and *"I am happy to die on a ventilator"*. On occasion this went as far as requesting medical assisted dying: *"euthanasia is acceptable to me"*. There was a desire for good communication and honesty from HSCPs to help facilitate these decisions: *"I would want my healthcare team to be honest and direct with me. I want shared decision making and would want to discuss my diagnosis and prognosis".*

Whilst a desire for autonomy and control over decisions was most common, others wished for family members to take over the decision-making role at the point of incapacity: *“I would want my wife to be kept fully informed and her views to be taken as if my own if I was not able to communicate”*. Others wished for HSCPs to take the lead: *“I want the doctors to do what they think is best”*. A specific decision which was frequently mentioned was the location a respondent would choose to die, often specifying home, hospice, or reporting a desire to avoid hospital: *“that I would prefer to be cared for in a hospice”* and *“I would not want to be admitted to an acute hospital when I am dying”*. Many respondents focussed on decisions to be taken following their death. These included the desire for organ donation: *“I would want organ donation to be considered”*, and for funeral arrangements: *“I want to be cremated”*.

Some respondents talked of an acceptance of death as inevitable: *“I am at peace and ready for my time when it comes”*, but a particularly important decision was how respondents would gauge the appropriate time to transition from *‘the end of life’* phase to the *‘dying phase’*. Many respondents used the loss of physical or mental capabilities as a marker of when it would be time to forego treatment and accept dying: *“not to have treatment which would leave me disabled”* and *“I don't want life to continue once I am unable to communicate”*. Others expressed fears about overtreatment with procedures and tests which would cause discomfort but would be ultimately futile: *“do not subject me to futile treatments, endless rounds of blood tests, cannulas etc.”*, and a desire to *“not have death prolonged”*. The importance of quality as opposed to quantity of life was frequently mentioned as important to respondents when thinking about treatment decisions: *“only perform treatments that will improve quality of life rather than just life prolonging”*. This married with a desire to prioritise enjoyment of life during the *‘end of life phase’* such as travel and performing loved activities: *“one last sail in my beloved gaff rigged cutter”*. Some respondents added the caveat that these priorities may well change over time, with changing family circumstances, or through the progression of illness: *“my views will change as my children get older”*. As well as a desire to maintain independence and quality of life some respondents discussed a fear of becoming a burden and a desire to choose earlier dying as a way of avoiding this: *“I do not want to be a burden to my family and society”*. A minority held a view contrary to this acceptance of dying. They were concerned that they would not be offered potentially beneficial treatments: *“don't let anybody write a DNAR form, because it might stop any treatable condition being considered”*, and would wish to prolong life even at the cost of pain and discomfort: *“I value life and would want everything possible to be done to prolong life”*.

4.3.6.2 Care

The *‘care’* that people wish during the *‘dying phase’* was a prominent consideration of respondents. In this context *‘care’* is distinct from *‘treatment’*. The focus of *‘care’* is on protection and a desire to avoid damage or harm. It is characterised by what it prevents, whilst treatment focusses on what it can achieve. Treatment is a means to an end with an ultimate goal in mind. In contrast *‘care’* is an end in itself. It is possible for a treatment to be successful / unsuccessful, whereas care is present or absent. *‘Care’* also denotes a much more paternalistic relationship where responsibility is placed on the *‘carer’* to avoid doing things which would be damaging and to protect or mitigate external factors which could cause suffering: *“I do not want to suffer while I am dying”*. Respondents frequently mentioned the importance of being treated with *“respect”*, *“dignity”,* and *“compassion”*: *“I am still a person with emotions and feelings, and want to be treated with dignity, kindness and respectfully”*. Some respondents expressed a wish for death to be *“peaceful”* and *“calm”* avoiding the distress that can come from *“heroics”*. One of the most forceful examples of the paternalistic relationship that people expect at the EoL is the request to be *“allowed to eat and drink whatever I want”*. For some there appears to be a concern that care may be lacking, perhaps borne of personal experience as HSCPs: *“to remember, and treat me as a person, not a diagnosis, not a failure of treatment”*.

One of the most common desires of respondents was to be *“comfortable”* and for adequate symptom relief: *“symptom control over everything else”*. Primarily this was mentioned in the context of *“good analgesia”* and a desire to be *“pain free”*, but for some nausea or breathlessness were major concerns: *“I don't want to feel sick, that is the worst feeling”*.

4.3.6.3 Family and Friends

Family and friends have already been mentioned in the context of decision making but their importance and role extended far beyond this.

During the *'end of life phase'* respondents reported the desire to spend time with their family and friends: *"I would prefer to spend meaningful time with people I love rather than prolong life but be unable to be myself around my loved ones".* Particularly during the *'dying'* phase, many respondents spoke of this desire *"to be with my nearest and dearest at the end"* and *"for my immediate family to be with me at the moment of my death, but only if they were comfortable with the thought of doing that".* This concern for the wellbeing of family and friends and the impact that the dying and death of the respondent would have was another important sub-theme: *"I don't want them to see me suffer"*. This sometimes linked to a desire for a quicker death, or to at least avoid the prolongation of death, in case it caused increased suffering to others: *"I want my children's needs to be put first. I would like them to remember me as I am. If that means dying earlier so be it."* There was a fear that family and friends would feel responsibility and guilt for the death and some respondents displayed a desire to try and avoid or mitigate this: *"they are not to feel guilty about anything, I have made my choices".* Others wanted to communicate their love and appreciation: *"my gratitude for all they have made my life"*. Many respondents expressed a desire to ensure that their family and friends are well supported during this time by others: *"take care of my friends and family - help them bear their pain"*.

For some, religious and spiritual beliefs were important. This manifested in the way respondents wished to be treated during the *'dying'* phase: *"let my parish priest give me my last rite"* and *"I would like to die as Muslim and final rituals as per Muslim faith"*. It could also act as a comfort and a way of alleviating fear of death for the individual and their loved ones: *"my faith is important to me and means death can be something to look forward to".* Others had explicitly anti-religious sentiment and wanted this reflected in their care as they approach death: *"no religious or superstitious process, practitioners, priests, chaplains etc."*

When thinking of the period *'after death'* concern about the impact on loved ones was also present. Some mentioned fears of who would take care of dependents: *"to know* *my children will be cared for"*, whilst others were concerned about the financial impact that their death may cause loved ones: *"that my death would not cause financial implications on my family"*.

Table 17 Main Free-Text Findings BC

Themes	**Main issues mentioned in each theme**	**Illustrative quotations**
Decision making	Maintaining autonomy and control.	*“as long as I am able to make decisions, the decisions are mine and I want you to respect them and support me”*
	Intensity of treatment and transition point to move towards palliative care Often focussed on particular medical treatments.	*“not to have treatment which would leave me disabled”*
	Desire for honesty and communication to aid decision making.	*“I would want my healthcare team to be honest and direct with me …”*
	Others who should make decisions should the respondent by incapacitated.	*“I would want my wife to be kept fully informed and her views to be taken as if my own if I was not able to communicate”*
	Decisions after death such as organ donation and funeral arrangements.	*“I would want organ donation to be considered”*
Care	How the respondent should be acted towards.	*“I am still a person with emotions and feelings, and want to be treated with dignity, kindness and respectfully”*
	Symptom relief Avoidance of pain and nausea	*“symptom control over everything else”.*
Family and Friends	Desire to spend remaining time with loved ones.	*“I would prefer to spend meaningful time with people I love rather than prolong life but be unable to be myself around my loved ones”*
	Concern about the impact of death and dying on their loved ones.	*“I don’t want them to see me suffer*
	Avoidance of being a burden	*“I want my children’s needs to be put first. I would like them to remember me as I am. If that means dying earlier so be it.”*
	Religious and spiritual beliefs	*“my faith is important to me and means death can be something to look forward to”*

4.4 Discussion

This workstream has developed and validated the *'bigconversations'* questionnaire, allowing the description of views, wishes, and preferences for EoL care. Alongside this, the questionnaire has been used to describe a cohort of UK doctors' own priorities for EoL care for the first time. It has detailed the most prominent and common opinions, but, the most interesting finding of this study is the variation of views that respondents have shown. There are undoubtedly broad trends: to be well informed; to avoid high-intensity medical treatments if terminally unwell; to spend remaining time with family and friends; and to be symptom free and well cared for. However, a substantial minority expressed different, indeed opposite, opinions. Some respondents would choose to be given minimal information and would prefer to delegate decision making to their healthcare team or family. For some, *'quantity' is* more important than *'quality'* and discomfort is a price worth paying in order to prolong life. Whilst a concern about overtreatment was more prevalent, others worried that they would not be offered potentially lifesaving, or life-prolonging, treatments. That variation exists in a relatively homogenous sample consisting solely of anaesthetists confirms there is no single definition of a *'good death'*. It is further evidence that ACP is fundamental to the task of providing good quality EoL care.

The qualitative analysis has allowed a much greater depth of understanding than could have been garnered from a quantitative questionnaire alone. The questionnaire was designed to cover the most important aspects of EoL care for an individual. The fact that the major themes of the quantitative questions: patient engagement; intensity of treatment; and the role of family and friends, were replicated in the qualitative analysis supports this. The qualitative component has also allowed the identification of new themes. The most interesting of these was that of a point of transition between curative and palliative treatments. The loss of physical or mental capabilities was often mentioned as the marker of when this transition should occur. The questionnaire made no mention of functional status, co-morbidities, or quality of life. It is likely that these factors would have a large impact on decision-making. A survey of US doctors found that there was declining accession to undergo CPR with increasing age and pre-existing co-morbidities, particularly Alzheimer's disease (253). This idea of a *'transition point'* marked by the loss of physical or mental capabilities is useful as it is applicable in all circumstances regardless of the cause of deterioration or of chronic disabilities. When considering ACP, often the cause and circumstances of future deterioration will be unknown. It can therefore be difficult for patients to accede to, or refuse, particular medical treatments as they may wish to make different choices in different circumstances. Information about a *'transition point'* could greatly help HSCPs when trying to make decisions in the patient's best interest.

The level of *'patient engagement'* (317) was measured in Q1-3 with most respondents favouring a high level of input. A desire for autonomy and control over decision making was a major topic of the qualitative analysis with a particular focus on medical decisions. This correlates with other work which has found that, in contrast to patients and families, doctors views of a good death are primarily *'biomedical'* in nature (318).

The intensity of treatment at EoL was explored in Q4, 5, and 9. Most respondents would choose to forego treatment aimed at prolonging life should that life be of poor quality and may avoid treatments which would prolong life at the expense of discomfort. A wish to avoid the *'medicalisation'* of death was reflected in both the free-text comments and in Q9 where the desire of most respondents was to avoid hospital as a place to die. A hospice was favoured by almost 2/3 of respondents. These preferences are similar, but more pronounced, than those of members of the public. Members of the public mostly want to avoid dying in hospital, but a home death is more heavily favoured (240,244–248). This may reflect an awareness, amongst this medical cohort, of the high care requirements that dying patients have, which may not be able to be met at home. Alternatively, given that the majority of these studies are from outside the UK, it may represent the greater prevalence and role of the hospice movement in the UK (319).

An interesting contrast within these findings arose when considering the role of family and friends. A major theme of the qualitative analysis was of the importance of family and friends: a desire to spend time with them; to avoid causing them suffering; and to not become a burden to them. Despite this, few wish to relinquish decision making should they disagree about medical treatments. For some, the desire for control and autonomy appears to be prized so highly that respondents are willing to tolerate the discomfort of family and friends in order to maintain it. In comparison, a Canadian study of patients with advanced chronic kidney disease found that 89% would want family/friends to make medical decisions for them should they lose capacity (246).

Two additional aspects which arose from the qualitative analysis were of the importance of *'care'* and the desire to make plans for *'after death'*. *'Care'* in this context is quite separate from treatment and revolves around the protection from harms and the importance of *"respect"*, *"dignity"*, and *"compassion"* from HSCPs. A harm which respondents desired protection from was that of the symptoms associated with dying. Concern about the undertreatment of pain is consistent across surveys of HSCPs (250,318), members of the public (240–242,320–323), and recently bereaved family members (254). It was similarly a significant finding in the qualitative analysis. Plans for *'after death'* included medical concerns such as organ donation as well as funeral plans, financial and estate issues, and caring responsibilities for other family members. These concerns have been highlighted as important in previous studies (241,243,254), with the exception of organ donation. Organ donation was particularly prominent in the free-text answers and this likely represents a nuance of this medical cohort. The idea of *'life completion'* (238) and *'a feeling of closure'* (239) have previously been described as important aspects of EoL care. The qualitative analysis did find references to *'saying goodbye'* and *'acceptance of dying'*, however, this idea of *'completion'* did not emerge as a major theme.

4.4.1 Limitations

This study must be considered with its strengths and weaknesses in mind. There is often a great deal of uncertainty about prognosis and therefore the likelihood of benefit of treatment to the patient (75,76,78,324–326). It was a necessary constraint of this study, and similar work involving both HSCPs (144,249,251–253,255–259) and members of the public (240,241,245–248,320,323,327–329), that the scenario clearly explains that the patient is dying. The complexities of real life can rarely be captured in such a one- or two-line narrative.

The response rate was 40%. This is actually slightly higher than the average of ~34% for online surveys involving the general population (330) and in keeping with an average response rate of ~38% for online surveys involving HSCPs (269).

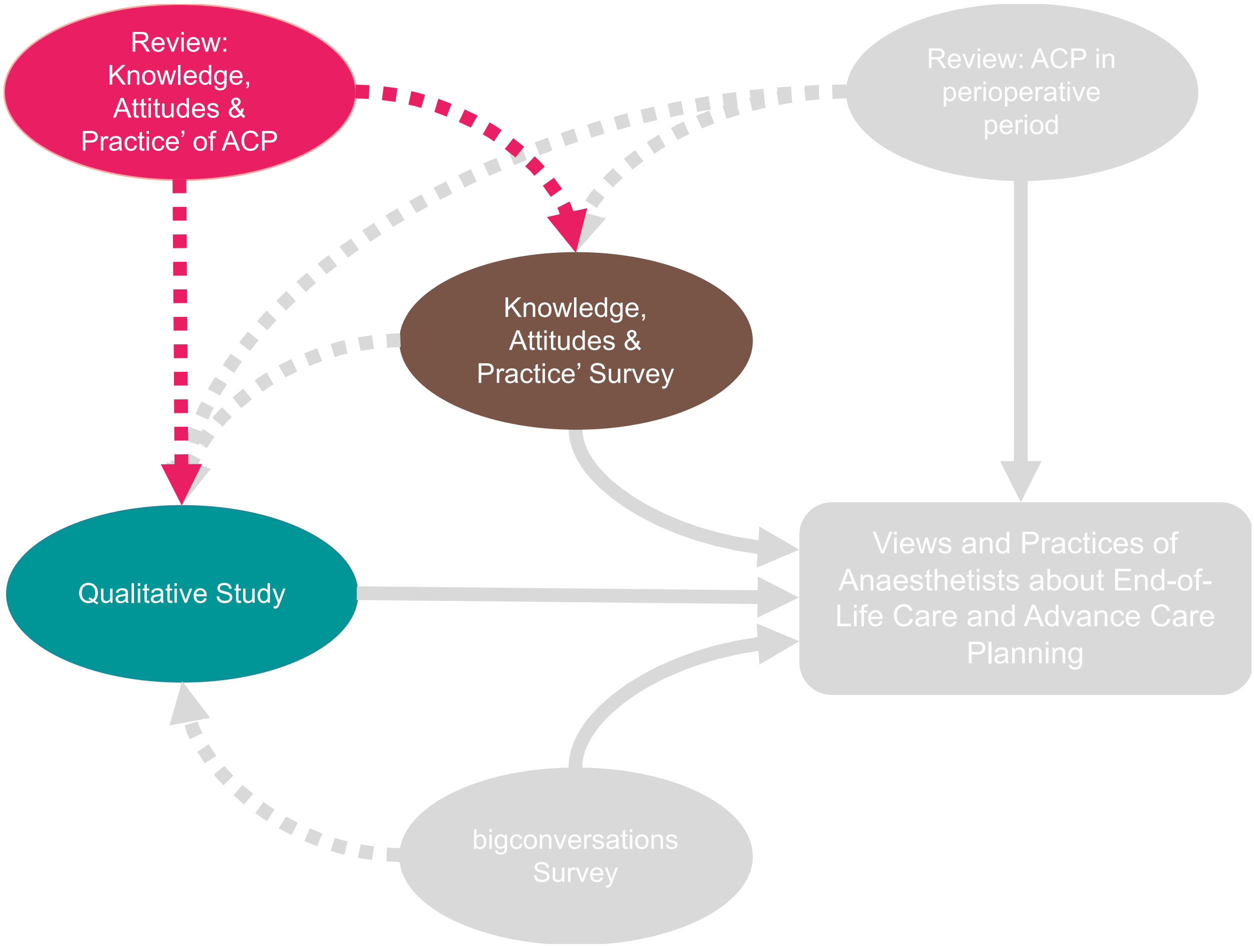
There is always a concern when conducting survey research of non-response bias. In an attempt to address this, respondents' characteristics were compared with known population characteristics. This comparison suggested that the sample underrepresented males and overrepresented Consultants. This may reflect actual differences between the sample and population. However, it may also represent a changing workforce since 2015, which is increasingly female and comprised of Consultants. Wave analysis was also performed which did not reveal a difference between the answers of early, middle, or late responders.

The calculation of reliability found that one question had substantial, seven moderate and one a fair level of agreement when assessed using weighted kappa. A partial explanation for Q1 showing only a fair level of agreement is the sensitivity that kappa has for distributional skew (331). When responses cluster in one category, as evidenced in Q1 where 76% were in a single category, kappa decreases even if there is high agreement between test and retest responses. The calculation of median differences allowed a quantification of the size of the changes between test and retest responses and the size of the median change was at most 1 even at the 99.4%CL. This shows that respondents' results were relatively consistent using the questionnaire and that there was not widespread misreading or misunderstanding.

4.5 Conclusion

This study has provided the first systematic description of UK doctors, specifically anaesthetists, personal preferences for EoL care. The findings support previous work suggesting that those who have experience of high-intensity medical treatments may choose to avoid these themselves. However, even within this population there remains a spectrum of opinion. This emphasises the importance of personalising EoL care and engaging in early discussion about values, wishes, and preferences prior to acute deterioration and loss of capacity. The qualitative component has provided significant additional insight. It reiterated the importance of patient engagement, treatment intensity, and the role of family and friends as key components of EoL care. It also highlighted new themes such as the transition between curative and palliative treatments, the importance of care as distinct from treatment, and after death planning.

5 Review of the Use of Knowledge, Attitudes & Practice Studies to Investigate Advance Care Planning



5.1 Introduction

The systematic review in Chapter 3 found a lack of information about HSCPs knowledge, attitudes, and practice of perioperative ACP. In particular no studies were found from the UK and only two involved anaesthetists.

A knowledge, attitudes, and practice study (KAP) is a well described research method which lends itself to exploring the issues of understanding, attitudes, and behaviour. For this reason, a KAP exploring anaesthetists and ACP was designed (KAP-ACP) which is described in Chapter 6. To guide the design and implementation of the KAP-

ACP a systematic review was conducted highlighting previous studies which had used a KAP to investigate ACP in any healthcare specialty and in all countries.

5.1.1 What is a KAP?

A KAP is a representative survey of a specific population to collect information on what is known, believed, and done in relation to a particular topic. Data can either be collected orally by an interviewer using a structured, standardised questionnaire, or, more commonly by a standardised paper or online instrument. The data can then be analysed quantitatively or qualitatively depending on the objectives and design of the study (332).

5.1.1.1 Origins in Family Planning

KAPs were first developed to measure hostility towards the organisation of family planning services in developing countries, with the first being a Puerto Rican study in 1948 (333). They were an extremely popular tool to assess views of family planning with around 400 KAPs undertaken in 67 countries between 1950-70 (334).

By the late 1960s concerns began to be raised about the scientific rigour of these studies and whether adequate efforts were made to ensure the validity and reliability of their results. KAP studies of this period have been described as a *"hybrid of public opinion poll, medical history and census interview"* (335) but they were given a renewed acceptability in the 1970s when the International Statistical Institute formed the World Fertility Survey (WFS) Research Program. The WFS was in effect an internationally developed and administered KAP (336). Although the main impetus behind the WFS was a political desire to show the need for family planning provision a major achievement of the WFS was to re-establish the validity of this survey methodology (337).

5.1.1.2 Evolution from Family Planning and Fertility

Whilst the vast majority of KAPs in the 1950-70's focussed on family planning and fertility, particularly in the developing world, the technique was adapted to explore other topics. A 1972 study (338) used a KAP to assess the impact of nutrition aides on knowledge, attitudes, and practice of rural homemakers and Chung (339) assessed knowledge, attitudes, and practice towards tuberculosis in Korea. KAPs have now become an established method to investigate health seeking behaviour and practice (340,341).

KAPs have also come to be used in a HSCP population. In 1976 a KAP was used to explore nutrition knowledge, attitudes, and practice of Canadian public health nurses (342). KAPs' advantages of speed, low cost, and the generation of quantitative data which can be inferred on to a larger population, has meant that they have been adopted on mass and are now a frequently used tool to assess both public and professional populations (341,343). They can reveal widespread misunderstandings, misconceptions, and obstacles to implementation or adherence of a policy or programme (160).

5.1.2 Objective of Review

Prior to developing any questionnaire it is recommended to conduct a literature review to identify existing psychometrically tested questionnaires (186,262). A major problem in research focussing on relatively subjective states is the proliferation of multiple questionnaires. This proliferation impedes research as there are significant problems generalising from one set of findings to another. Of course, appropriate questionnaire do not exist for every research question and it is often appropriate to develop a new measure. However, a common error is to dismiss existing questionnaires (262,344).

The goal of this review was to discover if any questionnaire previously described could be used, or minimally modified, thereby avoiding the creation of an entirely new questionnaire. Failing this, the review aimed to outline the knowledge, attitudes, and practice of ACP by HSCPs in different contexts. This would then be used to inform the design of a new questionnaire for use in the KAP-ACP and to inform the design of the QSE. Additionally, it was the intention to outline the methodology and quality of KAPs so that areas of good practice could be adopted, and methodological pitfalls avoided.

5.2 Methods

5.2.1 Design

The PRISMA statement was used to guide the review (221). A review protocol was registered in PROSPERO: registration number CRD42018055253.

5.2.2 Review Questions

The review was guided by the following questions:

I. Are any previously published KAPs investigating ACP suitable for use to investigate UK anaesthetists?
II. What are the barriers, or enablers, of ACP reported by HSCPs?
III. What is the methodology and quality of KAPs investigating ACP by HSCPs?

5.2.3 Search Strategy

A review of peer-reviewed journal articles using multiple databases was performed between February and April 2018: PubMed; Embase; CINAHL Plus; Web of Science; and ProQuest Central. Additionally, the grey literature was searched using the databases OpenGrey and Trip. The PICOS framework (222) was used to develop the search strategy (Table 18). The search used a combination of keywords and subject headings for the concepts of KAP, HSCP, and ACP / EoL decision making. An example search strategy can be found in Appendix 5. Results were combined into Mendeley (version 1.18; Elsevier, Amsterdam, Netherlands) and duplicates were removed. The reference lists of included articles were screened to identify additional relevant publications.

Table 18 PICOS Framework Used in the Development of Search Strategy SR-KAP

PICOS Element	Definition
Population	HSCPs
Intervention	Levels of knowledge, attitudes towards, and current practice of ACP.
Comparator	There was no ‘control’ group given the nature of this review.
Outcome	The primary outcome was to assess the reported levels of knowledge, attitudes towards and current practice of HCP in regard to ACP. A secondary outcome was to describe the methodology and quality of studies assessing HCPs knowledge, attitudes, and practice of ACP.
Setting	Any healthcare context.

5.2.4 Study Selection

The articles were screened by me and CVP in three phases (title and article type (DB), abstract (DB and CVP) and full text (DB and CVP) based on the following criteria:

- Fulfilled the definition of a KAP
- Focussed on HSCPs, and,
- Investigated ACP / EoL discussions.

When there was disagreement CVP and I discussed responses until agreement was reached.

USAID's definition of a KAP was adopted: "*a quantitative method (predefined questions formatted in standardised questionnaires) that provides access to quantitative and qualitative information"* (22). Studies which did not meet this definition or did not look at all three domains of knowledge, attitudes, and practice were excluded.

The definition of HSCPs was the same as that detailed in Section 3.2.4. The aim of this review was to include all those who could have ACP conversations with patients and so the definition of HSCP was kept as broad as possible.

This review looked at ACP discussions which necessitates that these are conversations about future care. In different countries, differing terminology is used to describe ACP. Every effort was made to include all studies which looked at this concept regardless of terminology.

Articles were not excluded based on publication date but only articles published in English were included.

5.2.5 Data Extraction

Study data were collected and managed using a data extraction form developed in Excel (version 16; Microsoft Corporation, Redmond, WA, USA). The categories used in the data extraction form are summarised in Appendix 6. The form was developed after the initial screening of full-text articles. The principal categories used in this form were knowledge, attitudes, and practice. Nine (345–353) of the eleven studies divided either the questionnaire or their results sections into these categories which guided data extraction. For those which did not answers were placed in the category that was felt most appropriate.

5.2.6 Data Synthesis

Data were exported from the spreadsheet and the main article characteristics collated and presented. As multiple different questionnaires were used with a wide degree of variation in terms of questions and topics covered it was not possible to undertake meta-analysis or other statistical techniques. Instead a qualitative approach was adopted. Articles were analysed using thematic analysis (299) to allow for the identification of patterns across the data set. A broadly descriptive type of thematic analysis was employed when developing the themes. The articles were read numerous times to ensure immersion with initial notes made of potentially interesting aspects. The entire data set was then coded. A review of the coding of the dataset, including the codes used, was performed by CVP. The dataset was then reread and recoded with codes added, modified, or removed as required to ensure the dataset was coded consistently. Potential themes were then identified with relevant data collected under each theme. The quality of studies was assessed and reported separately.

5.2.7 Quality Assessment

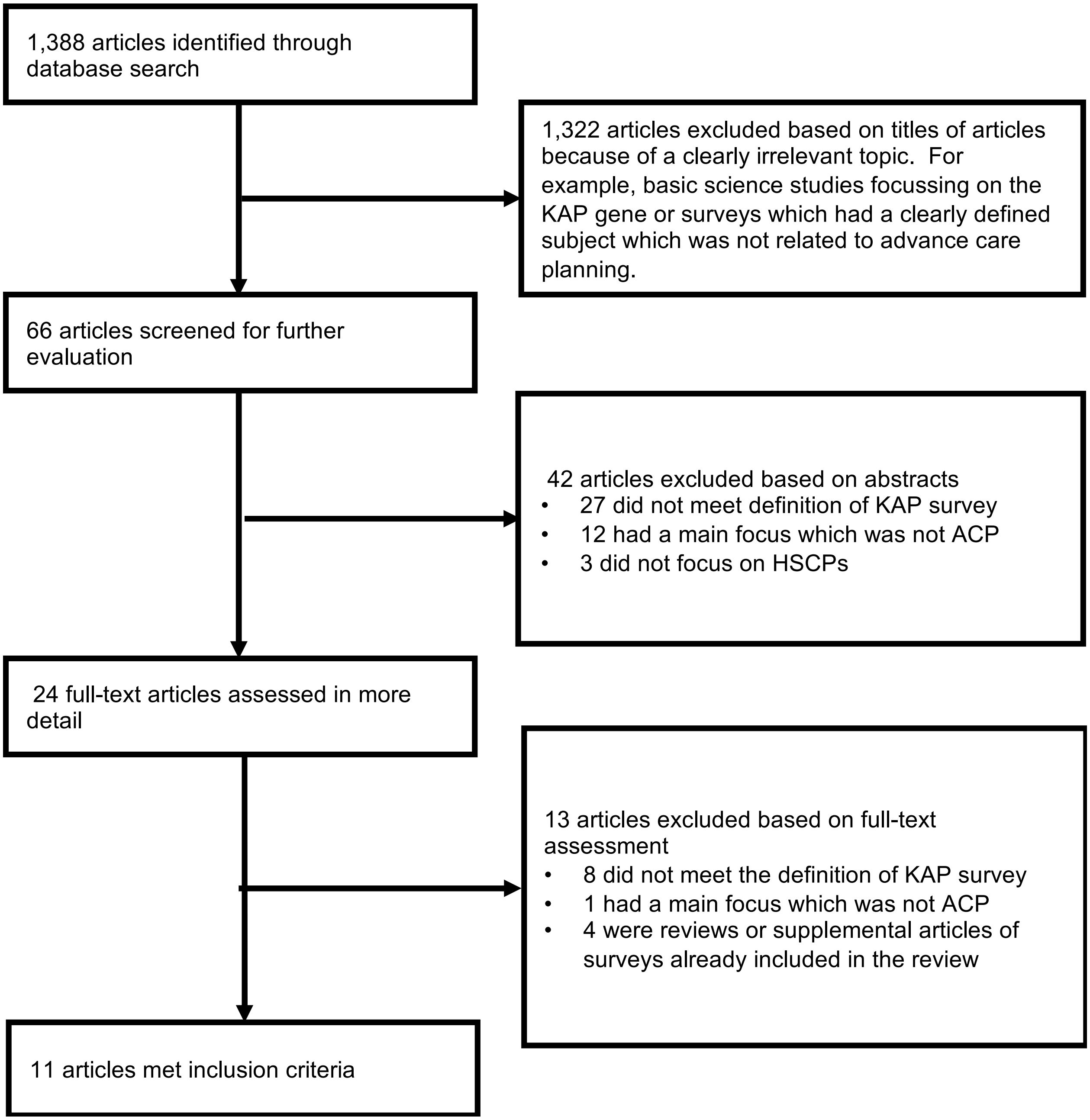
As previously discussed, currently there is no commonly used reporting guideline for survey research. Appendix 3 summarises the multiple checklists that have been described and/or used in the literature (186,188–190,261–265). The most detailed and well-evidenced of these is that by Bennett et al. (2011) (187) which reviewed the availability of guidance for reporting survey research from major journals as well as reviewing published studies on the quality of survey reporting. They identified 33 items as critical to reporting survey research. Each of these was used to assess the articles included in the review. Articles which reported >75% of these criteria were rated good; 50-75% moderate; and <50% poor.

5.3 Results

5.3.1 Identification of Studies

The initial search yielded 2,217 articles (206 from CINAHL; 482 from EMBASE; 634 from ProQuest; 238 from PubMed; 640 from Web of Science; 1 from OpenGrey; and 16 from Trip). Once duplicates were removed there were a total of 1,388 articles. These were screened based on title of article, resulting in 66 (Figure 12). Screening based on abstracts left 24 articles for full text review. Screening of the full texts led to 11 articles meeting the inclusion criteria. A review of the references of the articles did not find any further articles which met the inclusion criteria.

Figure 12 Study Selection Procedure for Reviewed Articles SR-KAP



One study (354) did not ask respondents questions about their knowledge of ACP. This study had a broader remit exploring the knowledge, attitudes, and experience of physicians in regard to palliative care and hospice care in addition to ACP. I discussed the inclusion of this study with CVP and we concluded that although the lack of knowledge questions about ACP was a limitation, the study still met the inclusion criteria of being a KAP and investigating ACP and therefore should be included.

5.3.2 Study Characteristics

The characteristics and results of the eleven studies included in the review are presented in Table 19. Eight of the articles originated in the USA, one was from Canada, one from Australia, and one from Ireland. Despite searching the grey literature no articles were found which met the inclusion criteria. The participants included nurses (eight), primary care physicians (one), home care package managers[††] (one) and nursing home managers (one).

[††] Home care package services are funded by the Australian Government to facilitate the provision of personal support and clinical care services to elderly clients (aged >65 years) so that they can remain at home for as long as possible. Case managers, in collaboration with the client and family, coordinate and reviews the care services the clients receive.

Table 19 Description, Including Results and Limitations, of Articles Included SR-KAP

Authors	**Country**	**Population**	**Knowledge**	**Attitudes**	**Practice**	**Limitations**
Downe-Wamboldt (1998)(352)	Canada	157/974 nurses	Nurses rated themselves as a mean of 7.4 on a 1-10 Likert scale (1 = very aware; 10 = not at all aware) of ACP/ADs.	Nurses had a mean score of 2.7 on a Likert scale (1=very helpful; 10=not at all helpful) when asked about ADs.	113/157 (72%) nurses stated they had no experience dealing with ADs.	Poor response rate.
			133/157 (85%) knew the meaning of power of attorney for healthcare.	Nurses had a mean score of 3 on a Likert scale (1=very helpful; 10=not at all helpful) when asked about the use of a surrogate.	120/157 (76%) nurses stated that they had no experience dealing with surrogates.	Respondents were more highly educated than the typical registered nurse in Nova Scotia.
			128/157 (82%) believed incorrectly that an AD should be followed in a situation in which a surrogate for an incompetent person disagreed with the living will.	One response reflected a negative experience with ADs: *"It is not easy, especially if you don't agree with the decision."*	The 37/157 nurses who reported experience with living wills indicated that the majority of their patients were >65 years old.	
				Nurses had a mean score of 9.2 on a Likert scale (1=agree strongly; 10=disagree strongly) when asked whether ADs restricted their nursing practice.	Nurses identified their role in relation to living wills as advocate (n=28), combination of roles (n=11), facilitator (n=5), and educator (n=2).	

				Nurses had a mean score of 9.1 on a Likert scale (1=agree strongly; 10=disagree strongly) when asked whether use of a surrogate restricted their nursing practice.	Nurses clearly identified lack of knowledge, legal concerns, lack of agency support, and ethical concerns as perceived barriers to the use of living wills in their practice.	
				Nurses had a mean score of 3.3 on a Likert scale (1 = totally agree; 10 = totally disagree) with the statement that nurses should promote the use of ADs and surrogates with all of their patients.		
				Benefits (n = 7) were described for family, patients, and nurses: *"I found a living will very beneficial to the care of my patients"*; *"Easier to deal with the family, patient more at ease"*; *"being aware of patient's and family's wishes makes nursing that person much easier."*		

Lipson (2004)(345)	USA	719/1600 nurses	Nurses scored well (95-99% correct) on questions referring to definitions of ADs.	Nurses recorded moderately positive attitudes towards ADs (M = 3.45; SD = 1.12; range of 1 to 5 with 5 = strongly agree and 1 = strongly disagree).	7.3% rated themselves as extremely confident in their skill level in discussing ADs with patients. 14% reported that they were not confident at all.	Self-reporting means that accuracy of information is a concern.
			57% nurses incorrectly answered a question referring to documentation of signing procedures.	Nurses disagreed that ADs represent an unwarranted extension of the law into medicine (M = 1.85; SD = .81).	15% had exposure to AD information in nursing school.	Single state sample limits generisability.
				Nurses disagreed prolonging life is more important than honouring a patient's request to forgo life-sustaining treatment (M = 1.41; SD = .63).	Higher age, greater years nursing experience, and higher level of education correlated negatively with reported levels of AD discussions with patients.	

Jezewski (2005)(346)	USA	791/3840 oncology nurses	Nurses scores were highest for the subscale assessing general knowledge of ADs including definitions, the role of surrogates, and some legal issues related to ADs. For this subscale the mean score was 7 out of a possible 10 (70%).	Respondents disagreed with statements stating that ADs will lead to acceptance of euthanasia and that denial of treatment for terminally ill patients because of cost is acceptable.	17% answered that they had provided treatment to patients whose AD indicated otherwise, and 42% had observed others providing treatment to patients whose AD indicated otherwise.	Low response rate (23%) meaning that non-response bias may be present.
				High level of agreement that nurses should uphold the patient's wishes even if they conflict with the nurse's own view.	52% agreed nurses often have insufficient time to discuss ADs with patients. Only 12% believed that nurses spend enough time discussing ADs with patients.	Results may not be generalisable to those outwith the 4 states surveyed.
				High level of agreement that patients with decision-making capacity who are not terminally ill should have a right to refuse life support even if that decision may lead to death.	Two-thirds or more of the nurses were confident (scores of 4 and 5 on the 5-point Likert scale) when discussing ADs with patients and families and answering their questions.	Low internal consistency for subscales about attitudes towards ADs and EoL care as well as professional experiences with ADs.
				High level of agreement that it is appropriate to give medication to relieve pain even if it may hasten a patient's death.	The qualitative component outlined the need for 1) education regarding ADs 2) more time to assist patients completing ADs 3) support from administrators and physicians regarding the nurse's role in helping patients complete ADs	

Scherer (2006)(348)	USA	210/1000 critical care nurses	Nurses scores were highest for the subscale assessing general knowledge of ADs including definitions, the role of proxy decision makers and some legal issues related to ADs. For this subscale the mean score was 7.07 out of a possible 10 (70.7%).	Most respondents (94.8%) agreed that nurses should uphold a patient's wishes even if the wishes conflict with the nurses' own view.	Most of the respondents had cared for a patient who had an AD (98.0%), counselled patients and patients' families about ADs (84.8%), and initiated discussion with patients about ADs (82.9%).	Low response rate.
				The respondents felt strongly (96.1% agreement) that patients should receive the pain medication they need even though the medication may hasten death.	48.1% of nurses had provided treatment to a patient whose AD had indicated otherwise. 71.3% of nurses had witnessed others providing treatment to a patient whose AD had indicated otherwise.	Results not generalisable outwith New York State and registered nurses.
				Agreement was high that nurses are responsible for conferring with a physician if a patient's rights have not been considered.	59.1% agreed nurses often have insufficient time to discuss ADs with patients. Only 12.6% believed that nurses spend enough time discussing ADs with patients.	Low internal consistency for attitudes to ADs and experience with EoL decision making.
				96.2% agreed that nurses should help inform patients of their condition and treatment options.	Respondents were most confident (scores >4) on items dealing with confidence in initiating (mean score 4.06, SD 1.05) and answering patients' (mean score 4.03, SD 0.98) and patients' families' (mean score 4.03, SD 0.96) questions about ADs.	

Duke (2007)(355)	USA	108/283 nurses	Only 7% were aware of competency requirements for an AD.	80% felt ADs were helpful.	56% had assisted a patient with an AD.	Small sample size.
			42% incorrectly thought that nutrition and hydration were included in comfort care.		In the open-ended question 3 respondents expressed concerns that wishes would not be honoured by physicians and/or families.	New tool lacked internal consistency.
					74% said they felt comfortable discussing ADs with patients, 14% neutral and 4% unfavourable.	Non-probability sampling.

Jezewski (2007)(347)	USA	579/3800 emergency nurses	Nurses scores were highest for the subscale assessing general knowledge of ADs including definitions, the role of proxy decision makers, and some legal issues related to ADs. For this subscale the mean score was 6.8 out of a possible 10 (68%).	High level of agreement that nurses should uphold the patient's wishes even if they conflict with the nurse's own view.	Over 76% answered yes to having cared for a patient with an AD, read their institutional policies/procedures concerning ADs, and initiated discussion about ADs with a patient.	Low response rate (17%).
				High level of agreement that nurses should help inform patients about their condition and treatment alternatives.	40% of the nurses had provided treatment to patients whose AD indicated otherwise and 63% of the nurses in the study had observed others providing treatment to patients whose AD indicated otherwise.	Low internal consistency for attitudes to ADs and EoL decision making. Also, there was low internal consistency for the subscale asking about opinions based on professional experiences with ADs.
				83% of nurses surveyed agreed that the presence of an AD encourages discussion between patients and providers.	Only 10% believed that nurses spend enough time discussing ADs with patients.	
				72% of emergency nurses agreed that patients misunderstand the meaning of ADs.	Nurses were confident in complying with the provisions of a patient's AD (74%) and advocating for patients' ADs when patient wishes conflict with the wishes of the family (60%).	

					Nurses wrote most frequently about the need for education about ADs and the lack of time to talk with patients in the emergency room impacting on AD completion.	
Putman-Casdorph (2009)(349)	USA	87/198 acute care nurses (general medical / surgical, cardiac) & inpatient & outpatient oncology nurses	Participants scored highest on general questions related to ADs such as questions about the purpose and function of living wills and medical power of attorney, with 95% to 100% of participants answering those questions correctly.	Participants responded with moderately negative attitudes overall toward ADs, with an aggregate mean score of 2.21 (SD = 0.84) and a range from 1 to 5. Higher mean scores were consistent with more positive attitudes	The experience mean score for the sample was 2.52 (SD = 0.83) when asked *“How often do you participate in discussions regarding ADs with your patients?”*. A lower mean score indicated greater numbers of these discussions with patients.	Small sample size. Poor response rate.
				Participants were also asked whether they considered AD discussions as one of their nursing roles. The mean score was 2.18 (SD = 1.03), with lower scores indicating that these discussions were part of the nursing role.	A higher mean score was associated with higher rates of perceived self-confidence. The sample for this study had a mean of 2.63 (SD = 0.78), indicating slightly to moderately confident perceptions. Only one participant reported feeling extremely confident with his or her ACP discussion skills. The majority of the sample participants were either slightly confident (n=23, 26%) or moderately confident (n = 50, 58%).	Only representative of one hospital.

Zhou (2010)(350)	USA	89/300 oncology advanced practice nurses	The average score of all respondents who answered the 12-item knowledge section correctly was 67% (range 33%–92%). The majority of respondents (88%) achieved greater than a 50% correct score.	In general, respondents scored positively in their attitudes toward ACP (mean = 1.91, SD = 0.37, range 1.5–2.52). Lower scores were consistent with positive attitudes.	Respondents scored only marginally positive in ACP practice behaviour statements that included initiating and following-up on ACP discussions and talking about options of hospice or palliative care with patients with advanced cancer and their families (mean = 2.62, SD = 0.45). Lower scores were consistent with greater experience.	Small sample size.
					When asked about whether they had ACP discussions with 50% or more of patients with advanced cancer in their practice, responses varied greatly (mean = 3.04, SD = 1.02). Lower scores represent positive behaviour.	Reliant on self-reporting.
					When asked about how often their collaborating oncologist(s) initiated ACP discussions, 44% said “sometimes,” and 37% said “often” (answer key = never, rarely, sometimes, often, always, don’t know).	Oncology APNs working at different practice settings may have different patient care foci. For example, APNs not involved in direct patient care or already working in hospice may not need to practice ACP.

						Because ACP is a value-laden practice, social desirability bias also may have influenced respondents' choices to certain survey items.
Snyder (2013)(354)	USA	158/372 primary care physicians		Many physicians felt that it was the patients and/or families themselves who erect barriers to successful ACP discussions.	44% percent of primary care physicians expressed the opinion that ACP discussions take too much time.	Poor response rate.
					Physicians report discussing ADs with only 43% of the patients they identified as having progressive, chronic life-limiting disease and only 61% of patients who are terminally ill.	Only representative of single geographic region.
				97.5% of physicians expressed comfort in discussing ACP.	54% of physicians responding believed that ACP should begin near disease onset, whereas only 4% believe this is when ACP actually occurs.	No questions asking about knowledge of ACP were asked.

Sellars (2015)(353)	Australia	178/962 home care package case managers	<50% felt confident regarding their knowledge and skills on eight ACP domains e.g. answering questions about ACP, knowing laws.	75% believed ACP was valuable and worthwhile for clients.	70% had initiated an ACP conversation in the previous 12 months, but 80% of the conversations did not progress to documentation of wishes.	Poor response rate.
				74% believed clients were more comfortable discussing ACP and EOL care in their own home.	65% were not satisfied with the time allowed to undertake ACP; 60% with lack of support from senior staff; 67% with the lack of appropriate documentation for recording outcomes; 78% with the lack of training; and 72% with the lack of written material to give to service users and their families.	Reliant on self-reporting.
				55% of case managers believed that they had a role in ACP.	Only 27% believed that the majority of clients were interested.	Risk of social desirability bias.
					66% felt comfortable discussing ACP with clients. Only 12% reported having a negative experience of ACP.	
					Only 48% (n=85) had previously completed any ACP training and only 30% (n=25) had that funded by their employer.	

Beck (2017)(351)	Ireland	116/178 nursing home mangers	The results demonstrated that nursing home managers' knowledge of ACP was poor, with less than half the sample (47% n = 54) being able to respond correctly to more than three of the seven knowledge questions.	Respondents highlighted the difficulty for nursing home managers in discussing death, with one participant stating *'death is a tough subject'*.	Less than half of nursing home managers perceived it to be their role (47% n = 54)	Self-reporting means that accuracy of information is a concern.
			ACP was viewed incorrectly as a legally binding document (41% n = 48), related only to medical interventions (50% n = 58) with little recognition of the voluntary nature of the process.	Barriers to ACP identified included: 1) lack of knowledge 2) time constraints 3) family conflict and the desire to protect the person from harm.	Those who had attended specific ACP training (24% n = 28) did not have improved knowledge as a result but they were likely to have a more positive attitude towards ACP.	Acknowledged risk of response bias.
				There was an assumption that people with dementia (81% n = 94) do not want to know about future care options.		Only represents single geographic region in UK.
				A considerable proportion of respondents also perceived that ACP may also impact negatively on a resident's sense of hope (34% n = 39)		

5.3.3 Survey Questionnaires

All studies were self-administered questionnaires either on paper (nine) or online (two). The majority (ten) used a mixture of closed and open-ended questions, however one study used purely closed questions (353). Eight studies described newly developed or modified questionnaires (345,346,350–355) whilst the other three used one of these eight questionnaires. A description of how survey questionnaires were developed and how validity and reliability were established is provided in Table 20.

Of the eight newly developed or modified questionnaires three provided the questionnaire in its entirety (351,353,354). Another could be deciphered from the presentation of the methods and results (350). For the remaining four studies the lead authors were contacted directly asking for a copy of their questionnaire. Three authors provided copies of the questionnaires (345,346,355). Only the Downe-Wamboldt questionnaire (352) was unavailable for analysis.

The seven available questionnaires were assessed to ascertain whether any could be used in its entirety or with only minimal modification. Unfortunately, none were felt to be suitable for the purposes of exploring the views and practices of UK anaesthetists towards ACP. The primary reason for this was that they often referenced law or organisational structures that are not relevant in the UK. The specific reasons for deeming each questionnaire unsuitable are detailed in Table 21

Table 20 Description of Questionnaire Development for Studies Included SR-KAP

	Downe-Wamboldt (1998)	**Lipson (2004)**	**Jezewski (2005)**	**Duke (2007)**	**Zhou (2010)**	**Snyder (2013)**	**Sellars (2015)**	**Beck (2017)**
How was the instrument developed?	New instrument developed by author. Based on literature review and using 9 questions from a previous piece of work 'Medical Consent Act' survey.	New instrument developed by author. Amalgamated 3 previously used questionnaires as well as new author developed items.	New instrument developed by author. Unclear how it was developed.	New instrument developed by author. Based on literature on the attitudes and practices of nursing personnel regarding ADs; round table discussion with practicing nurses; and the legislative mandates found in the PSDA and in Texas laws on ADs.	New instrument developed by author. Developed using Azjen's 'Theory of Planned Behaviour' as theoretical base. Questions were taken from previously developed surveys, developed using author's experience as Oncology APN, and several hospice and palliative experts recommendations.	New instrument developed by author. Unclear how it was developed.	New instrument developed by author. Based on literature and authors previous research.	The Zhou instrument was adapted to fit with the different context of care home managers.

How many items were in the instrument?	Not provided. Described as 12-page survey.	52	115	40	52	30	46	48
What were the type of quantitative questions used?	True / False	True / False	Yes / No / Don't know	Not reported.	Multiple choice	Multiple choice	Multiple choice	True / False / Don't know
	Yes / No	Yes / No	Likert scales		Likert scales	Asked to provide a percentage	Likert scales	Likert scales
	Likert scales	Likert scales				Likert scales		
What were the type and number of qualitative questions used?	Unknown number of open-ended questions.	2 open-ended questions.	1 open ended question.	1 open ended question.	7 open-ended questions.	1 open-ended question.	None.	3 open-ended questions.

How was validity established?	Content validity and clarity were assessed by a multidisciplinary panel of experts (lawyer, nurse, social worker).	The modified survey was evaluated for content validity by topic experts (two nurse-attorneys, one attorney specialising in elder law, and five nurses)	Content validity was evaluated by an expert panel. The panel members were experts in EoL care and ADs and represented the disciplines of nursing, medicine, law, and bioethics. The panel provided feedback on each of the 110 items included in the original draft of the survey. Changes were made to 22 items. Nine items were added, and four items were	Content validity was determined with a panel of five experts in nursing research and EoL care.	Content validity established by panel of 5 academic researchers and palliative care experts from several academic and clinical institutions.	Not established.	Not established.	Content validity established by 7-person panel consisting of experts in gerontology, palliative care and/or dementia.

			deleted based on the opinions of the panel and the judgment of the authors.					
How was reliability measured?		Test-retest for knowledge questions in pilot study. Cronbach's alpha was used for the entire study sample for the attitude questions.	Test-retest of the pilot survey was conducted and Cronbach's alpha was used to establish internal consistency (this was measured separately for each component part).	Internal consistency was calculated (unclear which technique was used).	1) Factor analysis performed, and 5 different factors found. 2 related to practice and 3 related to attitudes. Cronbach's alpha used to demonstrate internal consistency within these 5 factors. 2) Test-retest reliability for a subsample (53) and correlation coefficient calculated using Pearson's R.	Internal consistency calculated using Cronbach's Alpha for knowledge and attitude sections.	Not measured.	Internal consistency calculated using Cronbach's Alpha.

Table 21 Reasons for Unsuitability of Identified KAP Questionnaires

Questionnaire	Reason Deemed Unsuitable
Lipson (2004) (345)	Questions frequently reference US federal and Ohio state law.
Jezewski (2005) (346)	Questions frequently reference US federal and California, Illinois, New York or Texas state law.
	Long questionnaire consisting of 115 items.
Duke (2007) (355)	Questions frequently reference Ohio state law.
Zhou (2010) (350)	Questions frequently reference US federal law.
Snyder (2013) (354)	No knowledge questions focussing on ACP.
	Multiple questions focus on aspects of palliative and EoL care which are not related to ACP.
Sellars (2015) (353)	Multiple questions focus on funding structures for ACP used in Australia.
Beck (2017) (351)	Multiple questions focus specifically on patients with dementia.

5.3.4 Quality Assessment

The 11 studies were assessed using the 33 items identified as critical to reporting survey research by Bennett et.al. The results are presented in Table 22. One study was rated as of good quality (345) and the rest of moderate quality. Three studies provided the full questionnaire whilst seven provided core questions and only one failed to provide either. Five newly developed, or modified, instruments reported both the validity and reliability, one reported validity only, one reported reliability only and one reported neither. Three studies used a previous instrument and referenced the original paper reporting both validity and reliability. All studies reported the response rate and ten defined how this was calculated. Three studies discussed the representativeness of the sample, and five identified how missing data were handled.

Table 22 Quality Assessment of Methodology of Studies Included SR-KAP

	Downe-Wamboldt (1998)	**Lipson (2004)**	**Jezewski (2005)**	**Scherer (2006)**	**Duke (2007)**	**Jezewski (2007)**	**Putman-Casdorph (2009)**	**Zhou (2012)**	**Snyder (2013)**	**Sellars (2015)**	**Beck (2017)**
Title and Abstract											
Is the design of the study design reported in the title and/or abstract?	Either title or abstract	Either title or abstract	Either title or abstract	Either title or abstract	Either title or abstract	Either title or abstract	Either title or abstract	Either title or abstract	Either title or abstract	Both title and abstract	Both title and abstract
Introduction											
Is there an explanation of why the research is necessary, placing the study in context of previous work in relevant fields?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is the purpose or aim of the paper explained?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Methods Research Tool											
Is the questionnaire described?	Questions not provided	Core questions provided	Core questions provided	Core questions provided	Core questions provided	Core questions provided	Core questions provided	Core questions provided	Questionnaire provided	Questionnaire provided	Questionnaire provided
If existing tool - Are its psychometric properties presented?	N/A	Yes	N/A	Yes	N/A	Yes	Yes	N/A	N/A	N/A	N/A

If existing tool - Are references to the original work provided?	N/A	Yes	N/A	Yes	N/A	Yes	Yes	N/A	N/A	N/A	N/A
New tool - Are the procedures used to develop and pre-test it reported?	Develop only	N/A	Pre-Test only	N/A	Develop only	N/A	N/A	Both	Neither	Develop only	Both
New tool - Have its reliability and validity been reported?	Validity only	Both	Both	N/A	Both	N/A	N/A	Both	Reliability only	Neither	Both
Is a description of the scoring procedures provided?	Yes	N/A	N/A	Yes	No	Yes	Yes	Yes	Yes	N/A	Yes
Sample Selection											
Is there a description of the survey population and the sample frame used to identify this population?	Both	Both	Both	Both	Both	Both	Both	Sample frame	Sample frame	Both	Both
Do the authors provide a description of how representative the sample is of the underlying population?	Yes	No	No	No	No	No	No	No	No	Yes	Yes

Is a sample size calculation or rationale/justification for the sample size reported	Yes	Yes	Yes	Yes	No	Yes	No	No	No	Yes	No
Survey Administration											
Is the mode of administration reported?	Mail	Mail	Mail	Mail	In person - self administered	Mail	Mail	Online	Mail	Online	Mail
Do the authors provide information on the type of contact and how many attempts were made to contact subjects (i.e., prenotification by letter or telephone, reminder postcard, duplicate questionnaire with reminder etc.)?	Type and number	Type and number	Type and number	Type and number	Type only	Type only	Type only	Type and number	Type and number	Type only	Type and number
Do the authors report whether incentives were provided (financial or other)?	Not Reported	Yes. Incentive provided,	Not Reported	Not Reported	Not Reported	Not Reported	Yes. Incentive provided	Yes. Incentive provided	Not Reported	Not Reported	Not Reported

If reported, what incentive was provided.		50¢. donation to charity for each completed questionnaire					$10 gift card	$25 gift certificate			
Is there a description of who approached potential participants (e.g., identification of who signed the covering letter)?	No	No	No	No	No	No	No	No	No	No	Yes
Analysis											
Is the method of data analysis reported?	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Inadequate	Adequate	Adequate
Do the authors provide methods for analysis of nonresponse error?	No	No	No	No	No	No	No	No	No	No	No
Is the method for calculating response rate provided?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Are definitions provided for complete versus partial completions?	No	No	Yes	Yes	No	Yes	No	No	No	No	No

Are the methods for handling item missing data reported?	No	Yes	Yes	Yes	No	Yes	No	Yes	No	No	No
Results											
Is the response rate reported?	Yes, defined	Yes, defined	Yes, defined	Yes, defined	Yes, defined	Yes, defined	Yes, not defined	Yes, defined	Yes, defined	Yes, defined	Yes, defined
Are all respondents accounted for?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is information given on how non-respondents differ from respondents?	Issue addressed	No information	No information	No information	No information	No information	No information	No information	Issue addressed	Issue addressed	No information
Are the results clearly presented?	Yes, partial	Yes, partial	Yes, partial	Yes, complete	Yes, partial	Yes, complete	Yes, partial	Yes, complete	Yes, complete	Yes, complete	Yes, complete
Do the results address the objective(s)?	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Discussion											
Are the results summarized with reference to the study objectives?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Are the strengths of the study stated?	Yes	Yes	Yes	No	No	No	No	Yes	No	No	No

Are the limitations of the study (taking into account potential sources of bias or imprecision) stated?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is the generisability of the study results discussed?	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
Ethical Quality Indicators											
Study funding reported?	No	No	No	No	No	Yes	No	No	Yes	No	Yes
Research Ethics Board (REB) review reported?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Reporting of subject consent procedures?	No	Yes	No	No	No	No	Yes	Yes	No	No	No
Summary Score (Good = >75% of criteria met; Moderate = 50-75% of criteria met; Poor = <50% of criteria met)											
Percentage Score	63%	81%	72%	73%	56%	68%	65%	74%	65%	67%	74%
Rating	Moderate	Good	Moderate	Moderate	Moderate	Moderate	Moderate	Moderate	Moderate	Moderate	Moderate

5.3.5 HSCPs ACP Knowledge

Nurses rated themselves, and scored, highly on the more general questions about ACP/ADs including definitions and purpose (345–350) whilst nursing home managers and home care package case managers scored poorly and lacked confidence in their levels of knowledge (351,353). Questions about specific legislation whether that be national or state were typically answered poorly by all (346–352).

5.3.6 HSCPs Attitudes Towards ACP

Overall HSCPs had a positive attitude towards ACP/ADs (345,350,352,353,355) believing they were helpful (352,355), valuable, and worthwhile (353) although one study involving acute care and outpatient oncology nurses reported moderately negative attitudes (349). Three studies (345–347) found that nurses agreed that patients should have the right to refuse treatment even if to do so would lead to death and that patients should always be informed of their condition and treatment alternatives. A participant in one study (352) expressed difficulty when dealing with an AD when *“you don’t agree with the decision”* but three other studies (346–348) found a high level of agreement for the principle that nurses should uphold patients decisions even if they disagree. Two studies (349,352) found agreement that nurses consider ACP discussions as part of their role, whilst the studies involving home care package case managers (353) and nursing home managers (351) found around half agreeing that it was part of their responsibilities. The one study which focussed on physicians found that they felt that it was patients and/or families who erect barriers to successful ACP conversations. The study involving nursing home managers (351) found that they felt that their patients do not want to know about future options and that around a third felt ACP discussions may negatively impact a patient’s sense of hope.

5.3.7 HSCPs Practice of ACP

Studies demonstrated varying levels of experience of ACP/ADs with one finding 72% of nurses claiming no experience with ADs at all (352) whilst others found between 56-98% had cared for patients with an AD (347,348,355). Two studies found over 75% of nurses had initiated an ACP conversation with a patient (347,348). The study involving home care package case managers found 70% had initiated an ACP conversation in the last 12 months, although most of these did not progress to the documentation of wishes (353). Physicians reported only having ACP discussions with 43% of patients who were chronically ill and 63% of patients who were terminally ill (354).

In three studies, participants expressed concern that patients' wishes would not be respected despite having an AD (352,354,355). In another three studies (346–348), 17-48% of nurses reported having provided treatment prohibited by an AD themselves, whilst 42-63% had witnessed another HSCP doing so.

Seven studies highlighted insufficient time as a major barrier to having ACP discussions with patients (346–348,350,351,353,354). A lack of knowledge and training were also identified by nursing home managers and home care package case managers as a reason for these conversations not taking place (351,353). Staff discomfort and the difficult nature of talking about death was mentioned in two studies (350,351) and a lack of knowledge or desire on the part of patients and families was described in four (346,348,350,353).

5.3.8 Interactions of Knowledge, Attitudes, and Practice

Nine studies (345,347–351,354–356) reported on the interactions between knowledge, attitudes, and practice. Six studies showed a relationship between having greater knowledge and either having a more positive attitude (345,347,351), greater self-reported practice of ACP (345,350), or higher levels of comfort when having such discussions (345,348,355). Two studies reported that greater experience of ACP discussions resulted in greater confidence (346,349), more positive attitudes (346), and a greater perception of these discussions as being part of a nursing role (349). One study showed no correlation between physicians reported comfort levels with ACP and their reported number of referrals to hospice or palliative care (354).

5.4 Discussion

The primary goal of undertaking this review was to determine if a questionnaire already existed which could be used, or modified, for the purpose of investigating UK anaesthetists' knowledge, attitudes, and practice of ACP. Eight new or modified questionnaires were found in the literature, seven of which were reviewed in their entirety. Although none could be used in its original iteration, or even with minimal modification, they did inform the design of the KAP-ACP questionnaire and subsequently the interview guide for the QSE.

Many studies identified additional education and training as necessary for HSCPs in order to undertake ACP (345–347,349,351,352,354,355). Nurses tended to know about the generalities of ACP but lacked an in-depth knowledge of the law. This is in keeping with a previous review outlining nurse's knowledge of ACP (357). Whilst in-depth knowledge of legal nuance cannot be expected, a basic level of understanding, including how to help a patient write a valid AD, is necessary. The specifics of the knowledge section of the included questionnaires were the least helpful when designing the KAP-ACP. This was because only one study (351) originated from the UK and this was conducted in a jurisdiction, Northern Ireland, that has distinct legislation. Unlike the findings of the SR-pACP, the findings of the SR-KAP did support the hypothesis that lack of knowledge and training may be a barrier to ACP for HSCPs and therefore warranted investigation.

Whilst not universal, it was found that HSCPs were broadly supportive of ACP and felt it was valuable for their patients. Even though there were some exceptions, negative attitudes of HSCPs do not appear to be a significant barrier to ACP discussions. Some HSCPs did admit to discomfort and difficulty talking about EoL issues and some reported negative experiences either having ACP conversations or following a patient's AD. The majority of HSCPs however did feel comfortable and confident to engage in ACP and feelings of personal uneasiness were not seen as a major barrier. Conversely, the expectation of ACP causing discomfort to either the patient or their relatives, was more commonly cited as a block on having these discussions. This is similar to a previous review of HSCPs practice which identified concern about taking away patients' hope (358). Whether this is accurate or whether HSCPs use this fear of causing distress as an excuse for avoiding ACP is difficult to ascertain.

The most common barrier identified by HSCPs was a lack of time to have these discussions. In the context of a busy inpatient or clinic setting it may not be possible to dedicate the necessary amount of time to only one patient. The fact that the length of these discussions is unpredictable makes it additionally difficult for them to be scheduled within the working day. None of the studies asked respondents to rank how important they felt ACP was in relation to other tasks and roles. It is possible that HSCPs believe that ACP is positive and useful, but also think that it is of a much lower priority, or urgency, than other duties. A concerning finding of this review was that of HSCPs reporting that either themselves, or another, had acted against a patient's AD. HSCPs must respect the wishes of patients as expressed through ADs for the process of ACP to have any credibility.

A secondary goal of this review was to evaluate the methodology and quality of KAPs. As mentioned previously, there is a lack of validated reporting guidelines with which to assess quality. This was addressed by using well evidenced criteria to report indicators of quality, but it is not clear how many *'positive'* indicators would qualify a survey as of poor, moderate, or good quality and the cut offs that were chosen are arbitrary. This process did allow the highlighting of common errors when reporting survey research such as failing to explain how validity and reliability are established; failing to discuss the representativeness of the sample; and failing to identify how missing data was handled. This was helpful when designing the surveys in Chapters 4 and 6. Additionally, reviewing the methodology of these studies allowed the identification of techniques and strategies for establishing the validity and reliability of those surveys.

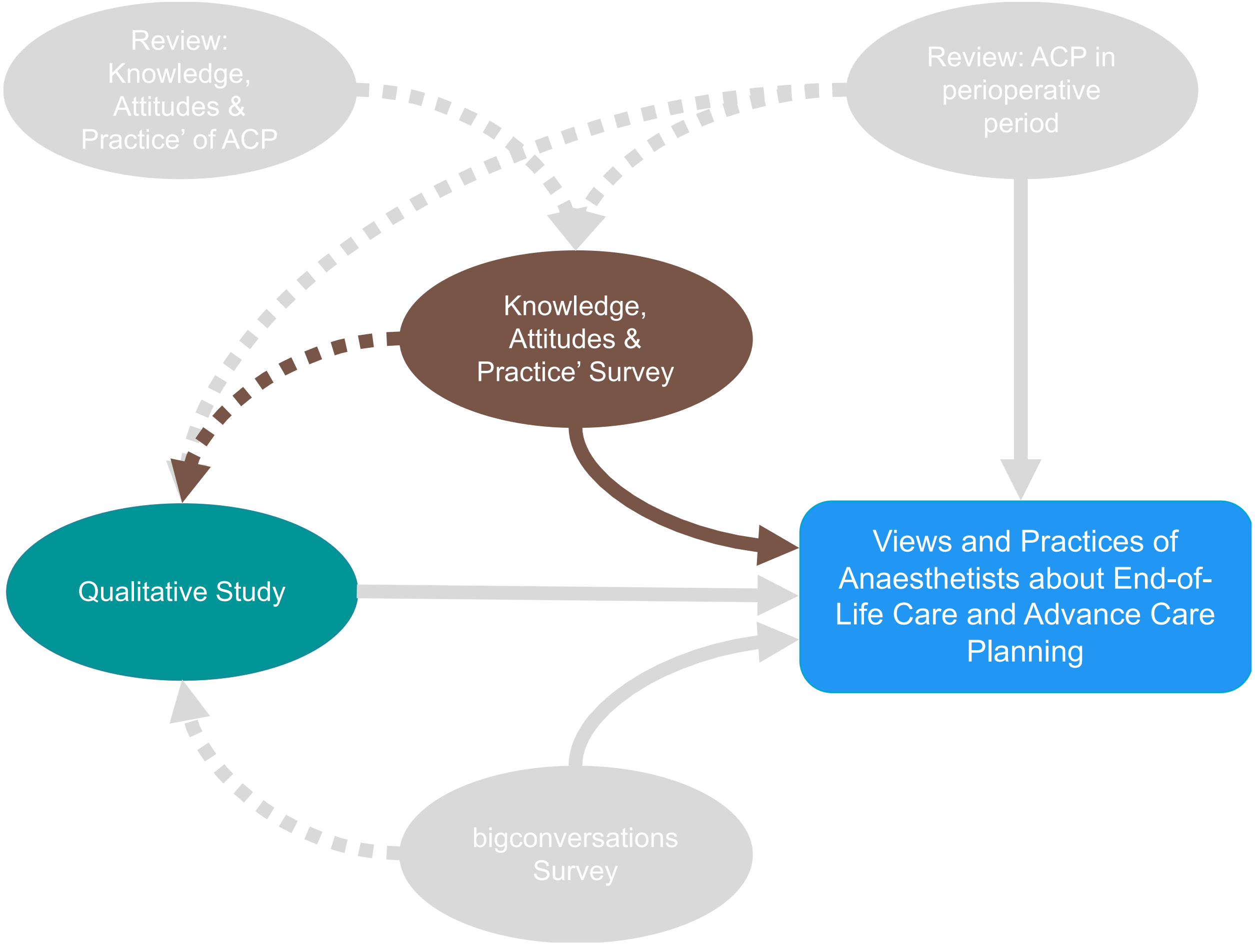
5.4.1 Limitations

This review should be interpreted with its limitations in mind. The broadest possible search terms were used, however, there may have been articles missed that did not use these. Although all studies were KAPs and therefore focussed on knowledge, attitudes, and practice there was a wide degree of variability of questions asked and topics covered. That studies from across the world were included is both a strength and weakness of this review. It provides as broad an outlook as possible, but the different legal and cultural considerations in different countries make it difficult to draw overarching conclusions. A potential disadvantage of KAPs is that they tend to eschew open-ended questions for the ease of data collection and so may not may not reveal new information or deepen understanding (359). When designing the KAP-ACP this was mitigated by allowing free-text comments for each question. A second caveat, which applies to all survey research, is that the practice, or behaviour, described is by necessity *reported* practice and therefore there is always a concern about informant accuracy (360). The choice of a mixed methods approach, as in this thesis, can mitigate both of these limitations by allowing for new ideas and concepts to be introduced by respondents and for *observed* practice to be reported.

5.5 Conclusion

A previously validated questionnaire which could be used to investigate UK anaesthetists' knowledge, attitudes, and practice of ACP was not found. The review did highlight several actual or potential barriers for HSCPs to ACP: a lack of knowledge and understanding; a lack of time; patient or HSCP discomfort; and a disregard or lack of faith in the impact of ACP. Finally, the methodology and quality of KAPs was described. These findings provided the framework for the design of the KAP-ACP and QSE.

6 Knowledge, Attitudes, & Practice Survey of Advance Care Planning in the Perioperative Setting



6.1 Introduction

The KAP-ACP workstream was designed to outline the knowledge, attitudes, and practice of UK anaesthetists towards ACP. A national survey was conducted using a newly designed questionnaire. The questionnaire was designed using the KAP framework outlined in Section 1.3.6 and the KAP methodology described in Section 5.1.1.

The findings from the SR-KAP and the SR-pACP were used to guide the development and implementation of this workstream. The SR-KAP influenced the design and methodology, and results from the SR-KAP and the SR-pACP were used to guide question development. Following the design of the questionnaire it was used to describe the views of UK anaesthetists. Similar to the BC workstream, the questionnaire was designed in a manner which allowed new issues to be raised by respondents.

6.2 Methods

6.2.1 Study Design

The framework outlined in Appendix 3, which was used in both the BC and SR-KAP workstreams, was used to guide the design and reporting of the KAP-ACP.

6.2.2 Description of Instrument

This workstream used a newly developed questionnaire (Appendix 7) consisting of 31 questions. The questionnaire is split into four principal sections: knowledge of ACP; attitudes towards ACP; current practice of ACP in any setting; and current practice of ACP in the perioperative setting.

The knowledge section consists of ten *true-false-don't know* questions. The attitudes section consists of nine statements to which respondents are asked to identify their level of agreement using a 5-point Likert scale (*Strongly Disagree* to *Strongly Agree*). The final question asks for a global assessment of the respondents' attitude towards ACP using a 5-point Likert scale (*Very Unsupportive* to *Very Supportive*). The general practice section includes four statements to which respondents are asked to identify their level of agreement using a 5-point Likert scale (*Strongly Disagree* to *Strongly Agree*). The final question is multiple-choice. The perioperative practice section consists of four statements to which respondents are asked to identify their level of agreement using a 5-point Likert scale (*Strongly Disagree* to *Strongly Agree*). The final question is multiple choice.

For all questions the option was available for respondents to make any further comments in a free-text comment box. At the end of the questionnaire respondents were provided with an open-ended question asking them to share any further thoughts on ACP. The goal of this *'general'* open question was to ensure that respondents had the opportunity to raise any important issues that they felt had been omitted (361).

6.2.3 Development of Questionnaire

The SR-KAP formed the basis for the development of the KAP-ACP questionnaire. As previously noted (Section 5.3.3), none of the identified questionnaires in the review were felt suitable to use in their entirety or with only minimal modification. The development of the new instrument was an iterative process utilising the questionnaires identified by the SR-KAP.

The seven questionnaires (345,346,350,351,353–355) identified by the SR-KAP were compiled in an Excel (version 16; Microsoft Corporation, Redmond, WA, USA) spreadsheet and divided into three categories: knowledge, attitudes, and practice. Four (345,346,350,351) had already divided their questionnaire into these categories. For the three which had not (353–355) each question was placed in the category felt most appropriate. Demographic questions were removed as demographic information for respondents had been previously recorded within the BC workstream. Questions irrelevant to a UK population were also removed. An example of this would be questions referring to US legislation such as the Patient Self-Determination Act (PSDA) and funding structures for Australian social care. In some instances, questions were modified to increase their relevance. An example of this would be questions from the Beck (351) questionnaire which reference ACP in regard to dementia. These were rephrased to be applicable to all patients. Questions which were similar in content were amalgamated.

This document consisting of questions from the seven identified KAP questionnaires (345,346,350,351,353–355) formed the basis of the KAP-ACP. The attitudes and practice questions were reduced to a total of ten items per section. The practice section was split into two: general and perioperative ACP. As none of the identified KAPs from the SR-KAP addressed perioperative situations these questions were informed by the findings of the SR-pACP.

The knowledge questions required considerable revision. This was because most knowledge questions from the identified KAPs referenced legislation not relevant in the UK. To create these questions guidance from the GMC (70); Royal College of Physicians (113); NHS Improving Quality (73); and the Mental Capacity Act (2005) Code of Practice (94) was reviewed in detail. Questions were then designed using information from these documents as their foundation.

6.2.4 Validity

The content validity of the KAP-ACP questionnaire was determined using the same process as described in the BC workstream.

6.2.4.1 Content Validity for KAP-ACP Questionnaire

To quantify the content validity the CVI was used (275). This involved multiple iterations. The first comprised an 8-member expert panel. 12 experts were initially chosen using the criteria outlined in Box 5 and asked to participate (276). 8 agreed to take part which matched the minimum of 8 recommended for the process to be valid by Polit et al. (275).

Box 5 Criteria for Appointment to Expert Panel for Content Validity KAP-ACP

Clinical experience with ACP and / or perioperative medicine
Professional certification in related area
Presented professional papers on related topic in regional / national / international professional meetings
Published papers on related topic in regional / national / international journals
Personal interest / experience of ACP

The composition of the panel is detailed in Box 6.

Box 6 Composition of Expert Panel for Content Validity KAP-ACP

Palliative Care Physicians (n = 2)
Critical Care & Anaesthesia Physician (n = 1) (also a medico-legal expert)
Anaesthesia & Perioperative Medicine Physicians (n = 2)
Professor of Nursing (n = 1)
Research Scientist with background in survey development (n = 2)

The process was identical to that carried out in the BC workstream (Section 4.2.4.1). The panel were asked to comment on three domains as recommended by Grant & Davis (277): the relevance of each question; the clarity of each question; and the comprehensiveness of the entire questionnaire. This process was conducted using an online form generated in SurveyMonkey (SurveyMonkey Inc., San Mateo, CA, USA).

This allowed for experts from across the country to take part at a time and place which was suitable for them.

6.2.4.1.1 Relevance

The I-CVI of each question was calculated and the S-CVI/Ave method used for each component of the questionnaire.

The results are presented in Table 23, Table 24, and Table 25. All questions, with the exception of one, had an I-CVI of 1. This means that all experts agreed that the questions were either *quite* or *highly* relevant. One question had an I-CVI of 0.88 because one expert felt that the question was only *somewhat* relevant. All questions met the threshold of >0.78. The S-CVI was calculated at 1 for the knowledge and practice components and 0.98 for the attitude component.

Table 23 Content Validity Index Values KAP-ACP (Knowledge)

Question	**Not Relevant**	**Somewhat Relevant**	**Quite Relevant**	**Highly Relevant**	**I-CVI**
K1. An advance care plan is not a legally binding document.	0	0	1	7	1.00
K2. ACP can only be undertaken by patients with capacity.	0	0	0	8	1.00
K3. An advance care plan only becomes valid if the patient lacks capacity.	0	0	1	7	1.00
K4. A patient's advance care plan must be adhered to even if the healthcare team believe the decision is not in the patient's best interest.	0	0	0	8	1.00
K5. A Lasting Power of Attorney for Health and Welfare (LPA) (Welfare Power of Attorney in Scotland (WPA)) gives another individual the authority to make healthcare decisions for a patient if they lack capacity.	0	0	0	8	1.00
K6. An LPA/WPA's decision must be adhered to even if the healthcare team believe their decision is not in the patient's best interest.	0	0	1	7	1.00
K7. A person can cancel a written advance care plan verbally if they have capacity.	0	0	0	8	1.00
K8. A family member can change the contents of a patient's advance care plan if the patient lacks capacity.	0	0	0	8	1.00
K9. During the ACP discussion, a family member or independent advocate must be involved.	0	0	0	8	1.00
K10. Patients cannot refuse an ACP discussion.	0	0	0	8	1.00
				S-CVI/Ave	1.00

Table 24 Content Validity Index Values KAP-ACP (Attitudes)

Question	Not Relevant	Somewhat Relevant	Quite Relevant	Highly Relevant	I-CVI
A1. ACP should be discussed with every patient regardless of how well or unwell they appear.	0	1	2	5	0.88
A2. Most individuals are sufficiently informed to make decisions about future treatment options.	0	0	1	7	1.00
A3. Most individuals don't want to discuss their wishes for future healthcare.	0	0	1	7	1.00
A4. ACP is upsetting for patients and their families.	0	0	2	6	1.00
A5. It is sometimes best to withhold information from patients and families.	0	0	2	6	1.00
A6. Patients frequently change their mind about life-sustaining treatment when they are unwell.	0	0	0	8	1.00
A7. Health professionals should uphold a patient's wishes even if it conflicts with their own view.	0	0	0	8	1.00
A8. An advance care plan is normally too ambiguous for it to be useful when making clinical decisions for an incapacitated patient.	0	0	0	8	1.00
A9. I have been in clinical situations where having a documented advance care plan would have been beneficial.	0	0	0	8	1.00
A10. What is your overall attitude towards ACP?	0	0	0	8	1.00
				S-CVI/Ave	0.98

Table 25 Content Validity Index Values KAP-ACP (Practice)

Question	Not Relevant	Somewhat Relevant	Quite Relevant	Highly Relevant	I-CVI
P1. It is my responsibility to discuss ACP with the patients who I see in my day to day practice.	0	0	0	8	1.00
P2. I feel comfortable discussing ACP with patients and their families.	0	0	0	8	1.00
P3. I have sufficient knowledge and training to discuss ACP with patients and their families.	0	0	1	7	1.00
P4. It would take too much of my time to discuss ACP with a patient.	0	0	0	8	1.00
P5. How often do you have ACP discussions with patients?	0	0	0	8	1.00
P6. Prior to major surgery is an appropriate time to have an ACP conversation.	0	0	0	8	1.00
P7. Pre-operative ACP would cause fear or unease for patients prior to surgery.	0	0	0	8	1.00
P8. Which healthcare professionals do you believe are best placed to initiate and have a pre-operative ACP discussion with a patient?	0	0	1	7	1.00
P9. I have cared / currently care for patients who would have benefited from having a pre-operative ACP conversation.	0	0	0	8	1.00
P10. I routinely have ACP discussions with patients prior to major surgery.	0	0	0	8	1.00
				S-CVI/Ave	1.00

6.2.4.1.2 Clarity

Prior to answering questions respondents were provided with the GMC definition of ACP (Box 1.1). Throughout this thesis the term ACP has been used to describe any discussion of wishes, preferences, and priorities and the term AD has been used to describe any documentation of these. To reduce the risk of misunderstanding for respondents this was altered within the KAP-ACP questionnaire. Within the questionnaire the term *advance care plan* is used to describe documentation as opposed to AD. This was done to minimise the confusion that may have occurred by introducing an additional term which may have been unfamiliar to respondents. When reporting results the term AD is used in keeping with the rest of the thesis.

Experts were asked whether each question was well written, unbiased, and at an appropriate reading level for medical professionals. The results are presented in Table 26, Table 27 and Table 28.

Table 26 Clarity of Questionnaire KAP-ACP (Knowledge)

Question	**Yes**	**No**
K1. An advance care plan is not a legally binding document.	6	2
K2. ACP can only be undertaken by patients with capacity.	8	0
K3. An advance care plan only becomes valid if the patient lacks capacity.	8	0
K4. A patient's advance care plan must be adhered to even if the healthcare team believe the decision is not in the patient's best interest.	5	3
K5. A Lasting Power of Attorney for Health and Welfare (LPA) (Welfare Power of Attorney in Scotland (WPA)) gives another individual the authority to make healthcare decisions for a patient if they lack capacity.	8	0
K6. An LPA/WPA's decision must be adhered to even if the healthcare team believe their decision is not in the patient's best interest.	6	2
K7. A person can cancel a written advance care plan verbally if they have capacity.	6	2
K8. A family member can change the contents of a patient's advance care plan if the patient lacks capacity.	7	1
K9. During the ACP discussion, a family member or independent advocate must be involved.	6	2
K10. Patients cannot refuse an ACP discussion.	8	0

Table 27 Clarity of Questionnaire KAP-ACP (Attitudes)

Question	Yes	No
A1. ACP should be discussed with every patient regardless of how well or unwell they appear.	7	1
A2. Most individuals are sufficiently informed to make decisions about future treatment options.	7	1
A3. Most individuals don't want to discuss their wishes for future healthcare.	7	1
A4. ACP is upsetting for patients and their families.	8	0
A5. It is sometimes best to withhold information from patients and families.	6	2
A6. Patients frequently change their mind about life-sustaining treatment when they are unwell.	8	0
A7. Health professionals should uphold a patient's wishes even if it conflicts with their own view.	7	1
A8. An advance care plan is normally too ambiguous for it to be useful when making clinical decisions for an incapacitated patient.	6	2
A9. I have been in clinical situations where having a documented advance care plan would have been beneficial.	8	0
A10. What is your overall attitude towards ACP?	8	0

Table 28 Clarity of Questionnaire KAP-ACP (Practice)

Question	Yes	No
P1. It is my responsibility to discuss ACP with the patients who I see in my day to day practice.	8	0
P2. I feel comfortable discussing ACP with patients and their families.	7	1
P3. I have sufficient knowledge and training to discuss ACP with patients and their families.	8	0
P4. It would take too much of my time to discuss ACP with a patient.	8	0
P5. How often do you have ACP discussions with patients?	7	1
P6. Prior to major surgery is an appropriate time to have an ACP conversation.	7	1
P7. Pre-operative ACP would cause fear or unease for patients prior to surgery.	8	0
P8. Which healthcare professionals do you believe are best placed to initiate and have a pre-operative ACP discussion with a patient?	8	0
P9. I have cared / currently care for patients who would have benefited from having a pre-operative ACP conversation.	7	1
P10. I routinely have ACP discussions with patients prior to major surgery.	5	3

Experts were asked to provide comments and examples if they were unhappy with the clarity of the current question. These comments were collated and used to modify the questions. These modified questions were then reviewed by the expert panel in an iterative process until agreement was reached. The original and modified questions are presented in Table 29, Table 30, and Table 31 with alterations highlighted in bold.

Table 29 Original and Modified Questions KAP-ACP (Knowledge)

	Original Questions	**Revised Questions**
K1.	An advance care plan is not a legally binding document.	An advance care plan is **always legally binding**.
K2.	ACP can only be undertaken by patients with capacity.	No changes.
K3.	An advance care plan only becomes valid if the patient lacks capacity.	No changes.
K4.	A patient's advance care plan must be adhered to even if the healthcare team believe the decision is not in the patient's best interest.	A patient's advance care plan **refusing treatment should** be adhered to even if the healthcare team **do not** believe **it is** the **correct** decision.
K5.	A Lasting Power of Attorney for Health and Welfare (LPA) (Welfare Power of Attorney in Scotland (WPA)) gives another individual the authority to make healthcare decisions for a patient if they lack capacity.	No changes.
K6.	An LPA/WPA's decision must be adhered to even if the healthcare team believe their decision is not in the patient's best interest.	An LPA/WPA's decision **should** be adhered to even if the healthcare team **do not believe it is the correct decision.**
K7.	A person can cancel a written advance care plan verbally if they have capacity.	A **patient** can **alter** a written advance care plan verbally if they have capacity.
K8.	A family member can change the contents of a patient's advance care plan if the patient lacks capacity.	No changes.
K9.	During the ACP discussion, a family member or independent advocate must be involved.	During the **initial** ACP discussion, a family member or independent advocate must be involved **and agree with the plan**.
K10.	Patients cannot refuse an ACP discussion.	No changes.

Table 30 Original and Modified Questions KAP-ACP (Attitudes)

	Original Questions	**Revised Questions**
A1.	ACP should be discussed with every patient regardless of how well or unwell they appear.	ACP should be discussed with every patient **when they visit a GP or hospital** regardless of how well or unwell they appear.
A2.	Most individuals are sufficiently informed to make decisions about future treatment options.	Most **patients** are sufficiently informed to make decisions about future treatment options **using an advance care plan**.
A3.	Most individuals don't want to discuss their wishes for future healthcare.	Most individuals don't want to discuss their wishes **about their** future healthcare.
A4.	ACP is upsetting for patients and their families.	No changes.
A5.	It is sometimes best to withhold information from patients and families.	It is **never acceptable** to withhold information **about diagnoses, treatments and risks** from patients and families.
A6.	Patients frequently change their mind about life-sustaining treatment when they are unwell.	No changes.
A7.	Health professionals should uphold a patient's wishes even if it conflicts with their own view.	Health professionals should uphold a patient's wishes **to refuse treatment** even if it conflicts with their own view.
A8.	An advance care plan is normally too ambiguous for it to be useful when making clinical decisions for an incapacitated patient.	An advance care plan is normally too ambiguous for it to be useful **to contribute to** clinical decisions for a **patient who has lost capacity.**
A9.	I have been in clinical situations where having a documented advance care plan would have been beneficial.	No changes.
A10.	What is your overall attitude towards ACP?	No changes.

Table 31 Original and Modified Questions KAP-ACP (Practice)

	Original Questions	**Revised Questions**
P1.	It is my responsibility to discuss ACP with the patients who I see in my day to day practice.	No changes.
P2.	I feel comfortable discussing ACP with patients and their families.	I feel comfortable discussing ACP with patients and **those important to them**.
P3.	I have sufficient knowledge and training to discuss ACP with patients and their families.	I have sufficient knowledge and training to discuss ACP with patients and **those important to them**.
P4.	It would take too much of my time to discuss ACP with a patient.	No changes.
P5.	How often do you have ACP discussions with patients?	How often do you have **any form of** ACP discussion with patients?
P6.	Prior to major surgery is an appropriate time to have an ACP conversation.	**The run-up** to major surgery, **e.g. pre-operative assessment clinic,** is an appropriate time to have an ACP conversation.
P7.	Pre-operative ACP would cause fear or unease for patients prior to surgery.	No changes.
P8.	Which healthcare professionals do you believe are best placed to initiate and have a pre-operative ACP discussion with a patient?	No changes.
P9.	I have cared / currently care for patients who would have benefited from having a pre-operative ACP conversation.	I have cared / currently care for patients who would have benefitted from having a pre-operative ACP **discussion**.
P10.	I routinely have ACP discussions with patients prior to major surgery.	I routinely have ACP discussions with patients **in the run up** to major surgery.

6.2.4.1.3 Comprehensiveness

Experts were asked to comment on the comprehensiveness of the questionnaire and whether there were any topics/areas which had not been included but should have been. Experts unanimously agreed that the questionnaire was comprehensive.

6.2.5 Sample Selection

6.2.5.1 Sampling Frame

The sampling frame for the KAP-ACP was respondents to the BC workstream who had agreed to be contacted about future research (n = 534).

6.2.5.2 Representativeness of Sample

This group was self-selecting as it included only individuals who had completed the *bigconversations* questionnaire and agreed to be contacted about future work. This may limit the representativeness of the sample but was a necessary restriction to ensure compliance with the GDPR and UCL ethics requirements.

6.2.5.3 Sample Size

As all potential respondents had agreed to be contacted about future work and there was no disadvantage in terms of cost or time, the entire group was surveyed.

In the same manner as the BC workstream a sample size calculation was performed to discover the minimum number of respondents required to give the desired level of precision. The sample size for this survey was calculated using Cochran's formula for sampling for proportions in a finite population (280) (Formula 2).

The same assumptions as described for the BC sample size calculation (Section 4.2.6.3) were applied in this case. The only difference was that the accepted margin of error was increased from +/-5% to +/-10%. This was a pragmatic decision. It was expected that the total number of respondents would be lower for the KAP-ACP than for the BC. The sampling frame was 534 compared to 1,913 meaning a similar response rate would result in a much smaller total number of respondents. Additionally, the KAP-ACP questionnaire was more labour intensive. It was estimated to take around 10 minutes in comparison to around 4 minutes for the bigconversations questionnaire. This was expected to decrease the response rate.

A sample size of 94 was calculated in order to provide a level of precision of +/-10% with a 95% chance that the true population value lies within this margin of error.

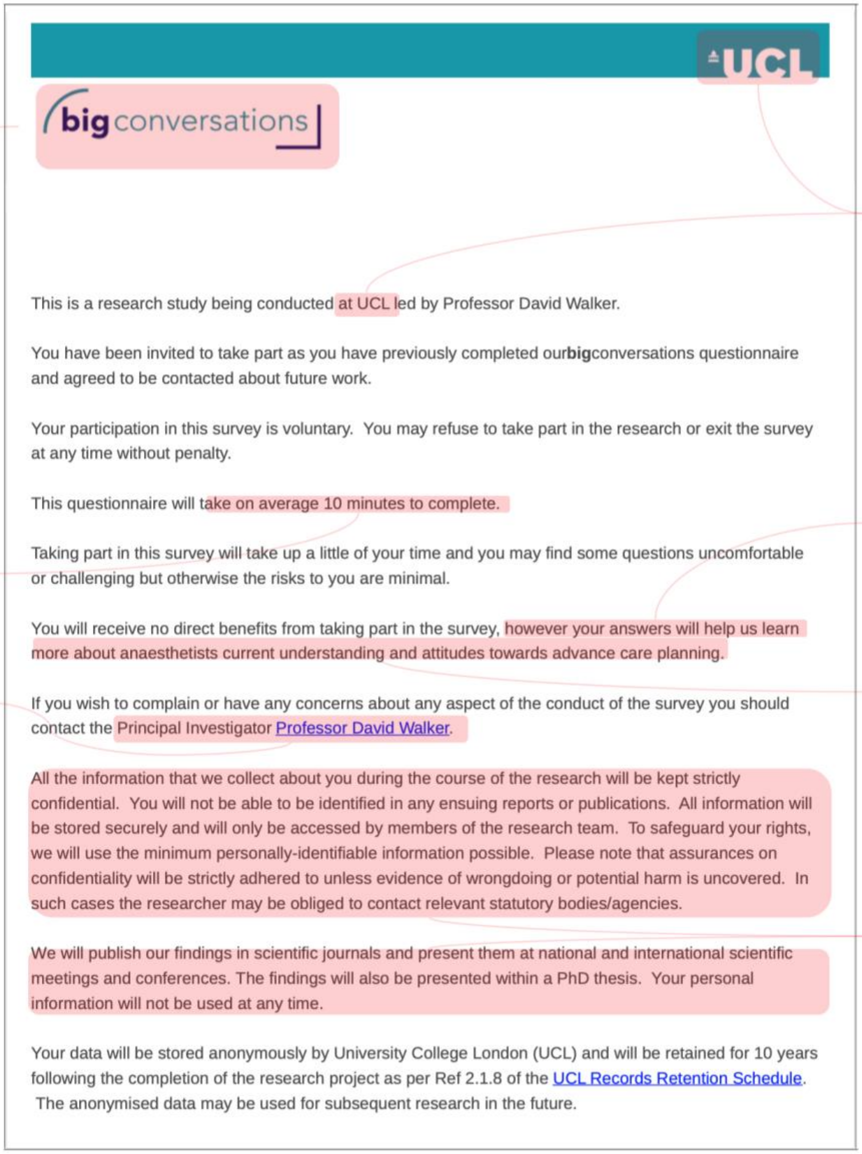
6.2.6 Survey Administration

The questionnaire was administered using the online survey platform SurveyMonkey (SurveyMonkey Inc., San Mateo, CA, USA). Potential respondents were contacted via email. No financial incentives were offered for participation for the same reasons described in Section 4.2.7.1. The design strategies described in Table 11 were applied when creating the instrument and invitation email (Figure 13).

The invitation email highlighted that participants had previously completed a similar piece of work. This was done to show that responding would be in keeping with previous behaviour. It provided a link to the preliminary results of the BC workstream to generate interest and provide a *'reward'* for taking part. Potential respondents were informed that the survey only took ~10 minutes on average to complete. This was done to both minimise the apparent cost, i.e. time, but also to infer that others had already responded.

In the same manner as the BC workstream the questionnaire introduction sheet acted as a consent form and participant information sheet.

Figure 13 Questionnaire Introduction KAP-ACP



This is a research study being conducted at UCL led by Professor David Walker.

You have been invited to take part as you have previously completed our**big**conversations questionnaire and agreed to be contacted about future work.

Your participation in this survey is voluntary. You may refuse to take part in the research or exit the survey at any time without penalty.

This questionnaire will take on average 10 minutes to complete.

Taking part in this survey will take up a little of your time and you may find some questions uncomfortable or challenging but otherwise the risks to you are minimal.

You will receive no direct benefits from taking part in the survey, however your answers will help us learn more about anaesthetists current understanding and attitudes towards advance care planning.

If you wish to complain or have any concerns about any aspect of the conduct of the survey you should contact the Principal Investigator Professor David Walker.

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. All information will be stored securely and will only be accessed by members of the research team. To safeguard your rights, we will use the minimum personally-identifiable information possible. Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the researcher may be obliged to contact relevant statutory bodies/agencies.

We will publish our findings in scientific journals and present them at national and international scientific meetings and conferences. The findings will also be presented within a PhD thesis. Your personal information will not be used at any time.

Your data will be stored anonymously by University College London (UCL) and will be retained for 10 years following the completion of the research project as per Ref 2.1.8 of the UCL Records Retention Schedule. The anonymised data may be used for subsequent research in the future.

bigconversations logo was used as a reminder of acquiescence to previous requests

Emphasis of support from 'legitimate' organisations

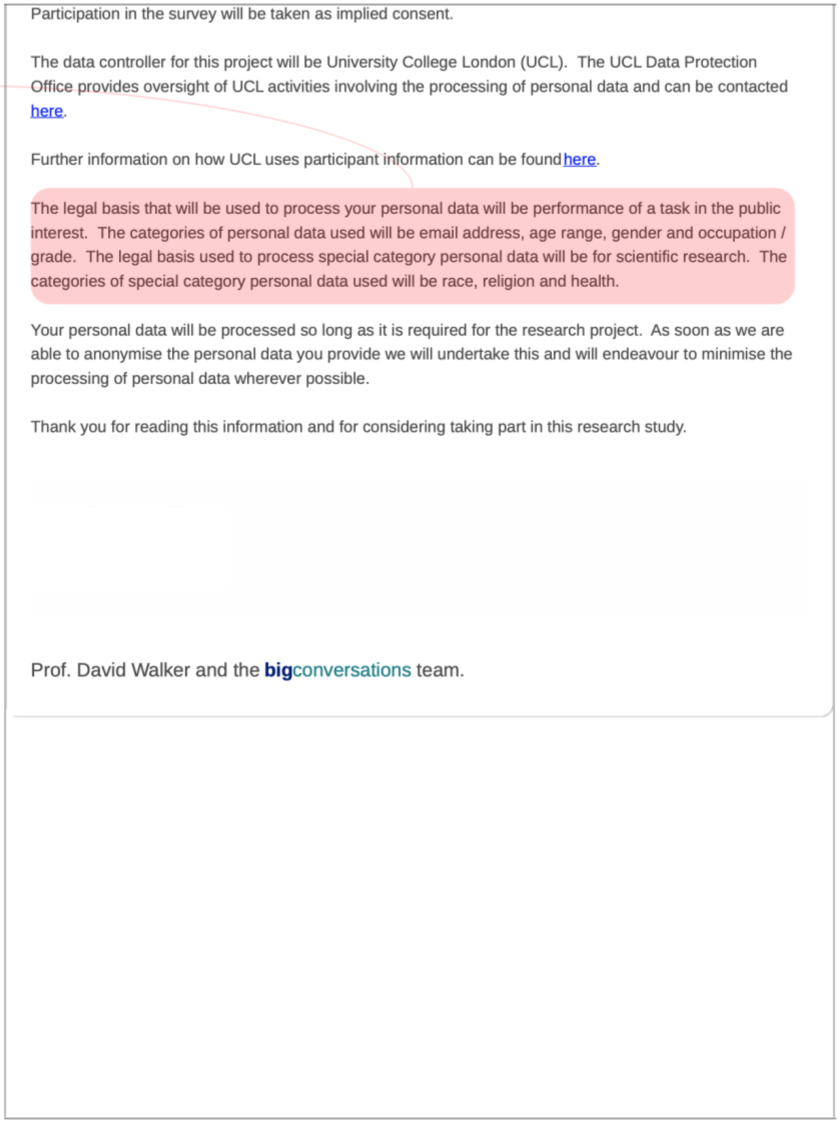
Providing an estimate of time-commitment and creating the impression that others have already responded

Request for help

Name and contact details easily available to promote trust

Emphasis on benefits to others

Emphasis on anonymity, confidentiality and data security



Requirement of GDPR

Participation in the survey will be taken as implied consent.

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data and can be contacted here.

Further information on how UCL uses participant information can be found here.

The legal basis that will be used to process your personal data will be performance of a task in the public interest. The categories of personal data used will be email address, age range, gender and occupation / grade. The legal basis used to process special category personal data will be for scientific research. The categories of special category personal data used will be race, religion and health.

Your personal data will be processed so long as it is required for the research project. As soon as we are able to anonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

Thank you for reading this information and for considering taking part in this research study.

Prof. David Walker and the **big**conversations team.

The survey was open from 17/7/19 until 2/9/19 with two reminders sent to those who had not taken part on the 31/7/19 and 14/8/19.

6.2.7 Analysis of Non-Response Error

Respondents demographic characteristics were compared to known population characteristics (288,290,293). Limited data about grade and gender were available from the RCoA's Medical Workforce Census Report from 2015 (215) and these were used for comparison.

Wave analysis was also performed to compare early and late responders (294). During the survey period respondents received an initial invitation (17/7/19) and two subsequent reminders (31/7/19 and 14/8/19). Answers to the knowledge component yielded categorical data and so this was assessed non-parametrically using Fisher's exact test. A Bonferroni corrected alpha level was calculated at 0.005. The attitudes and practice components were assessed non-parametrically using Kruskal-Wallis one-way and Cuzick trend analyses. A Bonferroni corrected alpha level was calculated as <0.0026. P8 included categorical data and therefore Fisher's exact test was used.

6.2.8 Incomplete Submissions / Missing data

Section 4.2.9 detailed concerns about the use of forced answering being unethical and resulting in poorer data quality. For these same reasons forced answering was not employed in the KAP-ACP workstream. Respondents were able to skip or leave blank questions if they so wished. The number of respondents for each question is presented with the results.

6.2.9 Reliability

Whilst reliability was calculated for the BC workstream using a test-retest method this was not possible for the KAP-ACP. The burden of answering 30 questions as opposed to 9 meant that it would be unreasonable to expect respondents to do this twice within the 4-6-week period required to perform a test-retest assessment of reliability. Given this internal consistency was calculated using Cronbach's alpha (302).

6.2.9.1 Alpha

Internal consistency estimates the inter-relatedness of items within an instrument and therefore the degree to which questions jointly measure the same construct (301). If the items do indeed measure the same construct they should be correlated to each other (362). An instrument has internal consistency to the extent that all the items measure the same construct (363).

Cronbach's alpha (Formula 4) is one of the most widely used measures of reliability in the social sciences (364). It measures the proportion of variance in total test scores which is *'shared'* between all items rather than unique to individual items (365).

Formula 4 Coefficient Alpha

$$\alpha = \left(\frac{k}{k-1}\right)\left(1 - \frac{\sum_i s_i^2}{s_t^2}\right)$$

$\boldsymbol{\alpha}$ = alpha
k = number of items
s_i^2 = variance of scores on item *i*
s_t^2 = variance of total test scores

Formula 4 is the formula for unstandardised alpha. Standardised alpha is calculated using correlation as opposed to covariance (366). If different items have uneven scales, i.e. some items use a 5-point Likert scale and some a 7-point scale, then these results must be standardised prior to providing a total score. In these cases standardised alpha should be used as variance between items will be partially dependent on the different scales (366). All scales in the KAP-ACP were of the same size in each component and therefore unstandardised alpha is reported.

Alpha was calculated separately for each of the three components: knowledge, attitudes, and practice. Having a large number of questions can artificially inflate the value of alpha even if there is relatively low correlation between items (367). As such it is advised that alpha should be calculated individually for each of the constructs being examined rather than the questionnaire as a whole (367). The 95% CI are presented with alpha as recommended by Bonett & Wright (364).

Alpha can be used in dichotomously scored items or with items with multiple response categories such as Likert data (301). Since alpha uses variance in its calculation it is strictly speaking a parametric statistic (368). It is however commonly used with Likert scale data which have a sufficient number of categories (normally 5 to 7) (366).

Questions in the knowledge section could be answered *'True'*, *'False'* or *'Don't Know'*. For the purposes of calculating alpha this data was treated as dichotomous: *'Correct'* or *'Incorrect'*. *'Don't Know'* answers were considered incorrect. P8 was a categorical question and was therefore excluded from the calculation of alpha. A3, A4, A6, A8, P4 and P7 were reverse scored prior to calculation of alpha.

The R package 'psych' was used to calculate alpha (369).

6.2.10 Data Analysis

Data were exported from SurveyMonkey (SurveyMonkey Inc., San Mateo, CA, USA) and uploaded to UCL Data Safe Haven. The analysis was conducted using the R Statistical Computing language (R version 3.5.0; R Foundation for Statistical Computing, Vienna, Austria).

6.2.11 Analysis of Free Text Answers

A *'general'* free-text open-ended question asking respondents to share any further thoughts on ACP was included at the end of the study. Additionally, because of the nuance and complexity of the ideas being explored each question in the attitudes and practice components provided the option for respondents to provide additional free-text comments.

Free text answers were compiled in a single list for each item and were left unedited (no corrections for spelling or grammar). Data were analysed using thematic analysis (299) to allow for the identification of patterns across the data set. A broadly descriptive type of thematic analysis was employed when developing the themes. Data were read numerous times to ensure immersion with initial notes of potentially interesting aspects made. Following from this the entire data set was coded. Potential themes were identified with relevant data collected under each theme and reread to ensure the themes identified appropriately captured the views and beliefs of respondents.

6.3 Results

The invitation to take part was sent to 534 potential respondents by email and 184 (34%) completed the questionnaire.

58% of respondents were male and 92% were between the ages of 25-65. Half of respondents worked solely within anaesthesia, a quarter within anaesthesia and ICM, and the rest had a mixture of roles including perioperative medicine and pain medicine. Consultants accounted for 72% of respondents. Almost all (97%) described their health *as 'good'* or *'very good'* and were not limited in their day to day activities (87.5%). 25% had caring responsibilities for others because of ill health or disability. 68% were white and 47% identified as Christian whilst 43% held no religion. Table 32 presents an overview of the demographic and personal characteristics of respondents.

Table 32 Demographic and Professional Profile of Respondents KAP-ACP

	n = 184
What is your sex?	
Male	106 (57.9%)
Female	77 (42.1%)
No Answer	1
What is your age?	
0-24	0 (0.0%)
25-44	73 (39.9%)
45-64	96 (52.5%)
65-74	12 (6.6%)
75+	2 (1.1%)
No Answer	1
Are you currently practicing in the UK?	
Yes	156 (84.8%)
No	28 (15.2%)
In what specialty (specialties) do you work?	
Anaesthesia	93 (50.5%)
Anaesthesia & Intensive Care Medicine	46 (25.0%)
Anaesthesia, Intensive Care Medicine & Perioperative Medicine	12 (6.5%)
Anaesthesia & Perioperative Medicine	11 (6.0%)
Intensive Care Medicine	7 (3.8%)
Other	4 (2.2%)
Anaesthesia, Intensive Care Medicine, Perioperative Medicine & Pain Medicine	4 (2.2%)
Anaesthesia & Pain Medicine	2 (1.1%)
Anaesthesia & Other	2 (1.1%)
Anaesthesia, Intensive Care Medicine & Pain Medicine	2 (1.1%)
Intensive Care Medicine & Perioperative Medicine	1 (0.5%)
What grade is your current post?	
Consultant	131 (71.6%)
Trainee	39 (21.3%)
SAS	9 (4.9%)
Other	4 (2.2%)
No Answer	1

How is your health in general?	
Very Good	114 (62.0%)
Good	65 (35.3%)
Fair	5 (2.7%)
Bad	0 (0.0%)
Are your day-to-day activities limited because of a health problem or disability which as lasted, or is expected to last, at least 12 months?	
Yes, limited a lot	0 (0.0%)
Yes, limited a little	23 (12.5%)
No	161 (87.5%)
Do you look after, or give any help or support to family members, friends, neighbours or others because of either; long term physical or mental ill-health / disability or problems related to old age?	
No	136 (73.9%)
Yes, 1-19 hours per week	42 (22.8%)
Yes, 20-49 hours per week	4 (2.2%)
Yes, 50 or more hours per week	2 (1.1%)
What is your ethnic group?	
White - Scottish / English / Welsh / Northern Irish / British	124 (67.8%)
Asian / Asian British - Indian	16 (8.7%)
White - Any other white background	11 (6.0%)
Other	8 (4.4%)
White - Irish	5 (2.7%)
Asian / Asian British - Chinese	4 (2.2%)
Black / African / Caribbean / Black British - African	3 (1.6%)
Asian / Asian British - Any other Asian background	2 (1.1%)
Mixed - Multiple ethnic groups - White & Asian	2 (1.1%)
Black / African / Caribbean / Black British - Caribbean	2 (1.1%)
Mixed - Multiple ethnic groups - White & Black Caribbean	2 (1.1%)
Asian / Asian British - Pakistani	1 (0.5%)
Arab	1 (0.5%)
Mixed - Multiple ethnic groups - Any other mixed / Multiple ethnic background	1 (0.5%)
Mixed - Multiple ethnic groups - White & Black African	1 (0.5%)
No Answer	1
What is your religion?	
Christian	87 (47.3%)
No Religion	79 (42.9%)
Hindu	11 (6.0%)
Muslim	2 (1.1%)
Other	2 (1.1%)
Buddhist	2 (1.1%)
Jewish	1 (0.5%)

6.3.1 Non-Response Error

The RCoA's Medical Workforce Census Report from 2015 (215) estimates that around 68% identify as male compared to 58% (95% CI 50-64%) of respondents. It also estimates that around 53% are Consultants compared to 71% (95% CI 64-78%) of respondents.

Respondents were divided into three *waves* to allow for wave analysis: early responders (n = 92); middle responders (n = 60); and late responders (n = 32). No statistically significant difference was detected between the waves at the Bonferroni corrected alpha level. Only P2 had a p-value <0.05 for both the Kruskal-Wallis and Cuzick trend analyses. P1 also had a p-value <0.05 for the Kruskal-Wallis but not Cuzick trend analysis. These results are presented in Table 33 and Table 34. Based on these results there is no evidence that there was a difference between early, middle, and late responders.

Table 33 Comparison Between Waves KAP-ACP (Knowledge)

Question	**p value for Fisher's exact test**
K1. An advance care plan is always legally binding.	0.67
K2. ACP can only be undertaken by patients with capacity.	0.70
K3. An advance care plan only becomes valid if the patient lacks capacity.	0.70
K4. A patient's advance care plan refusing treatment should be adhered to even if the healthcare team do not believe it is the correct decision.	0.79
K5. A Lasting Power of Attorney for Health and Welfare (LPA) (Welfare Power of Attorney in Scotland (WPA)) gives another individual the authority to make healthcare decisions for a patient if they lack capacity.	0.43
K6. An LPA/WPA's decision should be adhered to even if the healthcare team do not believe it is the correct decision.	0.57
K7. A patient can alter a written advance care plan verbally if they have capacity.	0.33
K8. A family member can change the contents of a patient's advance care plan if the patient lacks capacity.	0.15
K9. During the initial ACP discussion, a family member or independent advocate must be involved and agree with the plan.	0.71
K10. Patients cannot refuse an ACP discussion.	1

Table 34 Comparison Between Waves KAP-ACP (Attitudes & Practice)

Question	**p value for Kruskal-Wallis analysis**	**p value for Cuzick trend analysis**
A1. ACP should be discussed with every patient when they visit a GP or hospital regardless of how well or unwell they appear.	0.69	0.39
A2. Most patients are sufficiently informed to make decisions about future treatment options using an advance care plan.	0.99	0.89
A3. Most individuals don't want to discuss their wishes about their future healthcare.	0.70	0.98
A4. ACP is upsetting for patients and their families.	0.51	0.34
A5. It is never acceptable to withhold information about diagnoses, treatments and risks from patients and families.	0.50	0.42
A6. Patients frequently change their mind about life-sustaining treatment when they are unwell.	0.48	0.26
A7. Health professionals should uphold a patient's wishes to refuse treatment even if it conflicts with their own view.	0.40	0.84
A8. An advance care plan is normally too ambiguous for it to be useful to contribute to clinical decisions for a patient who has lost capacity.	0.11	0.04
A9. I have been in clinical situations where having a documented advance care plan would have been beneficial.	0.81	0.52
A10. What is your overall attitude towards ACP?	0.89	0.64
P1. It is my responsibility to discuss ACP with the patients who I see in my day to day practice.	0.04	0.40
P2. I feel comfortable discussing ACP with patients and those important to them.	0.04	0.02
P3 I have sufficient knowledge and training to discuss ACP with patients and those important to them.	0.34	0.15
P4. It would take too much of my time to discuss ACP with a patient.	0.73	0.71
P5. How often do you have any form of ACP discussion with patients?	0.16	0.20
P6. The run-up to major surgery, e.g. pre-operative assessment clinic, is an appropriate time to have an ACP conversation.	0.24	0.66
P7. Pre-operative ACP would cause fear or unease for patients prior to surgery.	0.49	0.72
P8. Which healthcare professionals do you believe are best placed to initiate and have a pre-operative ACP discussion with a patient?	0.72*	
P9. I have cared / currently care for patients who would have benefitted from having a pre-operative ACP discussion.	0.62	0.38
P10. I routinely have ACP discussions with patients in the run up to major surgery.	0.39	0.24
* calculated using Fisher's exact test as categorical data		

6.3.2 Reliability

Cronbach's alpha values were calculated for each of the questionnaire's components. These are reported in Table 35. A commonly reported *'acceptable'* alpha level is ≥0.70 (370). This has been adapted from Nunnally's recommendation that in the early stages of research one may work with instruments with *'modest'* reliability where reliabilities of 0.70 or greater will suffice (371). The KAP-ACP survey found that only the practice component reached this standard of *'modest'* reliability using internal consistency.

Table 35 Internal Consistency Values KAP-ACP

Subscale	**Alpha (95% CI)**
Knowledge	0.4 (0.27 to 0.53)
Attitudes	0.55 (0.45 to 0.65)
Practice	0.78 (0.73 to 0.83)

6.3.3 Anaesthetists' ACP Knowledge

The results demonstrated that respondents' knowledge of ACP appears high (Figure 14). All questions were answered correctly by a majority of respondents with the exception of K3 (39% answered correctly) and K6 (46% answered correctly). K6 asked whether an LPA/WPA's decision should be adhered to even if the healthcare team do not believe it is the correct decision. 33% answered incorrectly stating that the LPA/WPA's decision should not be adhered to in this circumstance.

Most respondents answered correctly that an AD is not always legally binding (76%) and that the process of ACP can only be undertaken by those with capacity (75%). Most correctly identified that an AD refusing treatment should be upheld even if the medical team do not believe it is the correct decision (71%) and that an LPA / WPA gives another individual the authority to make healthcare decisions if a patient has lost capacity (92%). Similarly, most answered correctly that: an AD can be altered verbally (87%); that a family member does not have the ability to alter an AD should a patient lack capacity (86%); the presence of a family member or independent advocate is not required during an initial ACP discussion (67%); and that patients are able to refuse an ACP discussion should they wish (92%). These results can be viewed in Figure 14 and Table 36.

Figure 14 Anaesthetists’ ACP Knowledge

Table 36 Anaesthetists' ACP Knowledge

Question	Incorrect	Don't Know	Correct
K1. An advance care plan is always legally binding.	17 (9%)	27 (15%)	140 (76%)
K2. ACP can only be undertaken by patients with capacity.	36 (20%)	10 (5%)	138 (75%)
K3. An advance care plan only becomes valid if the patient lacks capacity.	98 (53%)	14 (8%)	72 (39%)
K4. A patient's advance care plan refusing treatment should be adhered to even if the healthcare team do not believe it is the correct decision.	31 (17%)	22 (12%)	131 (71%)
K5. A Lasting Power of Attorney for Health and Welfare (LPA) (Welfare Power of Attorney in Scotland (WPA)) gives another individual the authority to make healthcare decisions for a patient if they lack capacity.	4 (2%)	11 (6%)	169 (92%)
K6. An LPA/WPA's decision should be adhered to even if the healthcare team do not believe it is the correct decision.	60 (33%)	40 (22%)	84 (46%)
K7. A patient can alter a written advance care plan verbally if they have capacity.	12 (7%)	12 (7%)	159 (87%)
K8. A family member can change the contents of a patient's advance care plan if the patient lacks capacity.	8 (4%)	18 (10%)	158 (86%)
K9. During the initial ACP discussion, a family member or independent advocate must be involved and agree with the plan.	28 (15%)	32 (17%)	124 (67%)
K10. Patients cannot refuse an ACP discussion.	3 (2%)	11 (6%)	170 (92%)

6.3.4 Anaesthetists' Attitudes Towards ACP

Respondents appear to be broadly supportive of ACP. This is evidenced by A10 where 43% are supportive and 49% very supportive of ACP. 91% report being in a clinical situation where they believe an AD would have been useful. They disagree with the idea that ADs are normally too ambiguous to be useful (60%). Most respondents feel that patients are sufficiently informed to make decisions via ACP (65%). They disagree with the idea that most individuals don't want to talk about these issues (56%) and disagree that ACP is upsetting for patients and families (48%).

There is agreement that HSCPs should not withhold information about treatments and prognoses from patients (62%) and that they should uphold a patient's wishes even if they disagree (92%).

Most disagree that ACP should be discussed with every patient when they visit a GP or hospital (53%). There is also moderate agreement with the idea that patients frequently change their mind when unwell (45%). These results can be viewed in Figure 15 and Table 37.

Figure 15 Anaesthetists' Attitudes Towards ACP

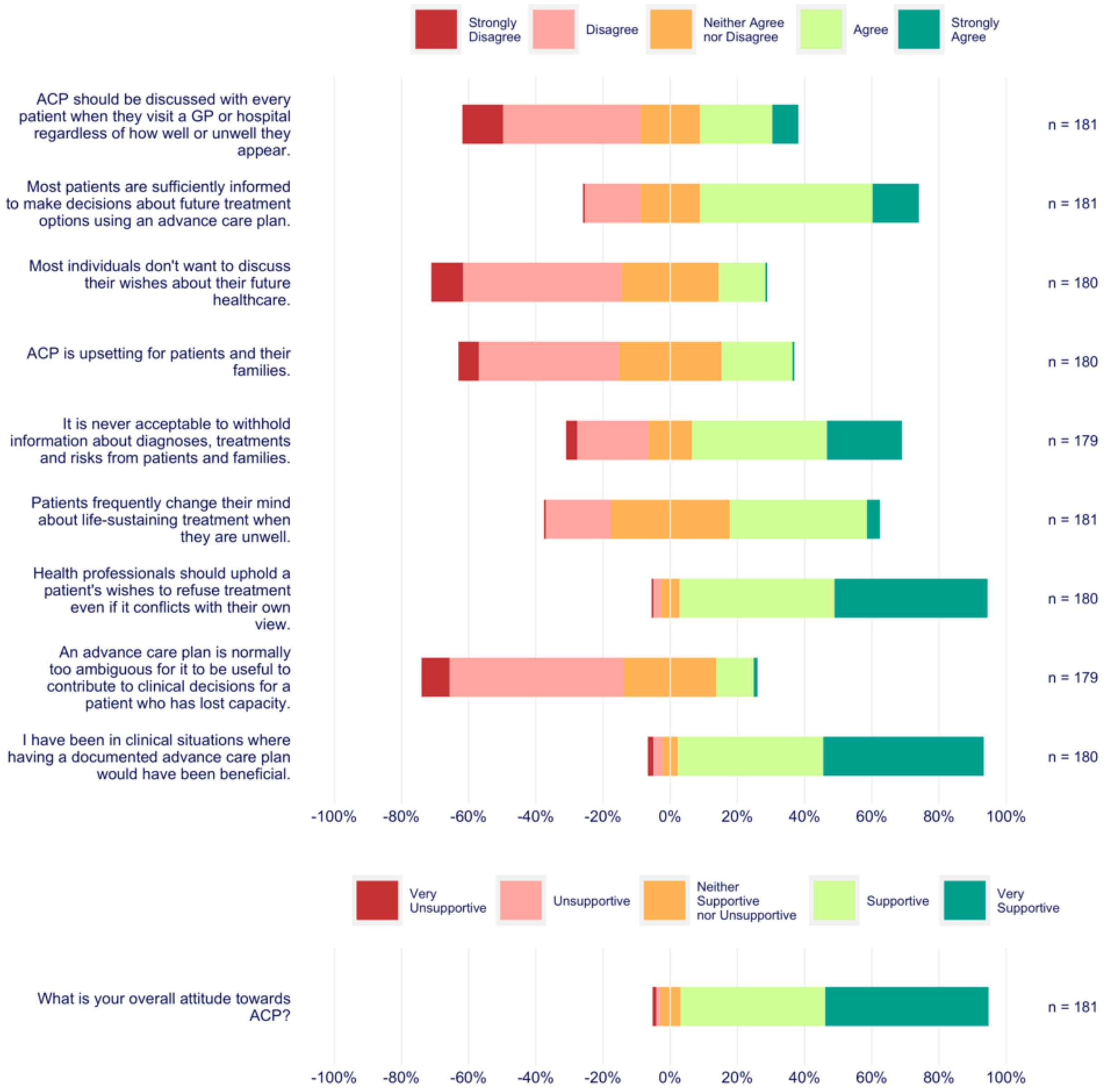


Table 37 Anaesthetists' Attitudes Towards ACP

Question	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
A1. ACP should be discussed with every patient when they visit a GP or hospital regardless of how well or unwell they appear.	22 (12%)	74 (41%)	32 (18%)	39 (22%)	14 (8%)
A2. Most patients are sufficiently informed to make decisions about future treatment options using an advance care plan.	1 (1%)	30 (17%)	32 (18%)	93 (51%)	25 (14%)
A3. Most individuals don't want to discuss their wishes about their future healthcare.	17 (9%)	85 (47%)	52 (29%)	25 (14%)	1 (1%)
A4. ACP is upsetting for patients and their families.	11 (6%)	75 (42%)	55 (31%)	38 (21%)	1 (1%)
A5. It is never acceptable to withhold information about diagnoses, treatments and risks from patients and families.	6 (3%)	38 (21%)	23 (13%)	72 (40%)	40 (22%)
A6. Patients frequently change their mind about life-sustaining treatment when they are unwell.	1 (1%)	35 (19%)	64 (35%)	74 (41%)	7 (4%)
A7. Health professionals should uphold a patient's wishes to refuse treatment even if it conflicts with their own view.	1 (1%)	4 (2%)	10 (6%)	83 (46%)	82 (46%)

A8. An advance care plan is normally too ambiguous for it to be useful to contribute to clinical decisions for a patient who has lost capacity.	15 (8%)	93 (52%)	49 (27%)	20 (11%)	2 (1%)
A9. I have been in clinical situations where having a documented advance care plan would have been beneficial.	3 (2%)	5 (3%)	8 (4%)	78 (43%)	86 (48%)
	Very Unsupportive	**Unsupportive**	**Neither Supportive not Unsupportive**	**Supportive**	**Very supportive**
A10. What is your overall attitude towards ACP?	2 (1%)	2 (1%)	11 (6%)	78 (43%)	88 (49%)

6.3.5 Anaesthetists' Practice of ACP

The majority of respondents' report having at least one ACP discussion with a patient every 6 months (54%). More agree (48%) than disagree (26%) that it is their responsibility to discuss ACP with the patients they see on a daily basis. There are split opinions on whether respondents feel they have sufficient knowledge and training to discuss ACP. 39% feel sufficiently equipped whilst 34% do not. Despite this 67% feel comfortable discussing ACP with patients and those important to them. Half of respondents do not believe it would take too much time to have ACP discussions (50%). These results can be viewed in Figure 16 and Table 38.

Figure 16 Anaesthetists' Practice of ACP

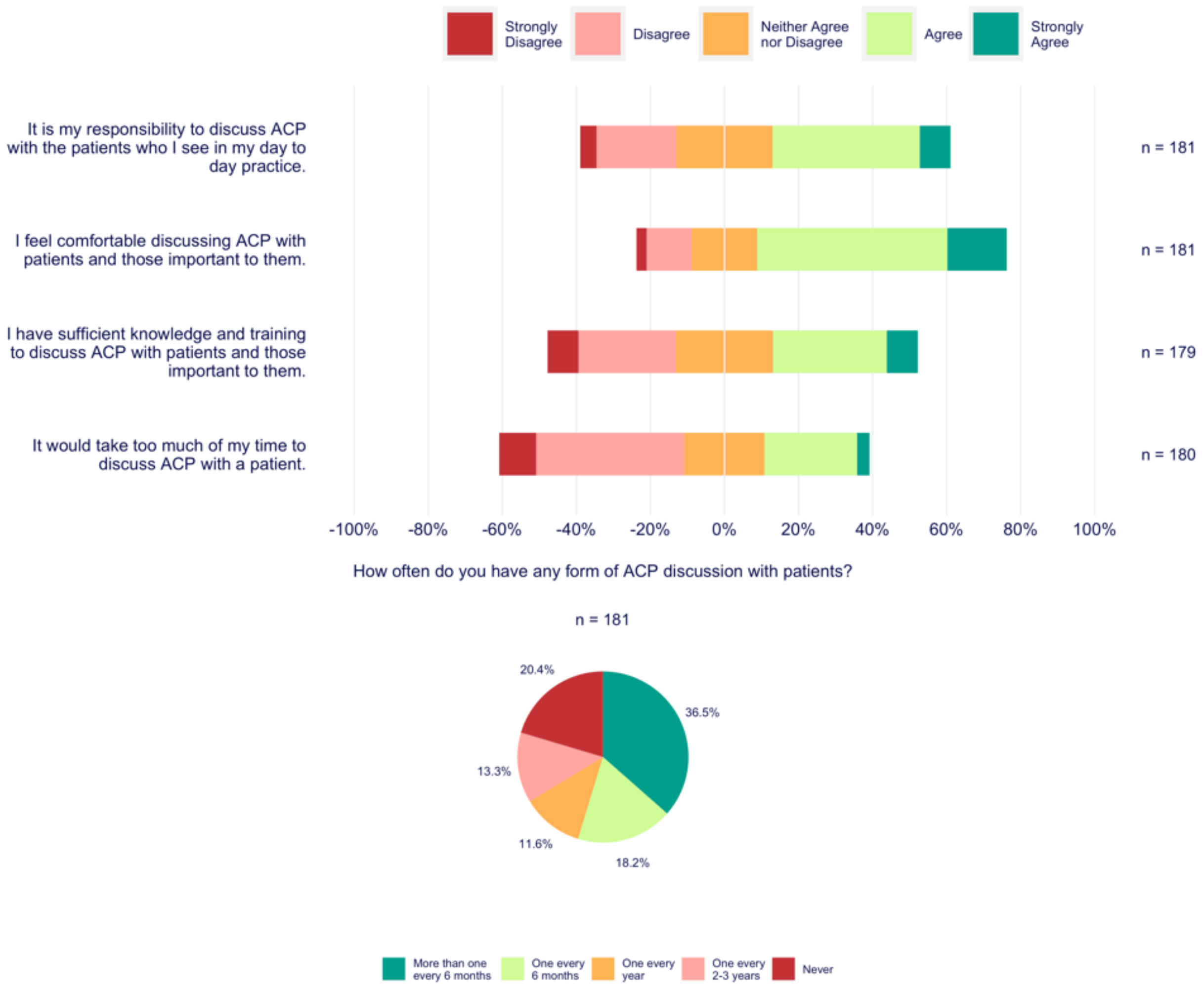


Table 38 Anaesthetists' Practice of ACP

Question	**Strongly Disagree**	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
P1. It is my responsibility to discuss ACP with the patients who I see in my day to day practice.	8 (4%)	39 (22%)	47 (26%)	72 (40%)	15 (8%)
P2. I feel comfortable discussing ACP with patients and those important to them.	5 (3%)	22 (12%)	32 (18%)	93 (51%)	29 (16%)
P3 I have sufficient knowledge and training to discuss ACP with patients and those important to them.	15 (8%)	47 (26%)	47 (26%)	55 (31%)	15 (8%)
P4. It would take too much of my time to discuss ACP with a patient.	18 (10%)	72 (40%)	39 (22%)	45 (25%)	6 (3%)
	Never	**Once every 2-3 years**	**Once every year**	**Once every 6 months**	**More than once every 6 months**
P5. How often do you have any form of ACP discussion with patients?	37 (20%)	24 (13%)	21 (12%)	33 (18%)	66 (36%)

There was a high level of agreement with the idea that the run-up to major surgery is an appropriate time to have an ACP conversation (78%). 82% report having cared for a patient who would have benefitted from a pre-operative ACP discussion. Only 25% believe that such a discussion would cause fear or unease for patients approaching surgery. Despite this only 25% consider this as part of their routine practice with patients in the run-up to major surgery. There was no unity on the specialty best-placed to initiate these discussions. Anaesthetists / perioperative physicians were favoured by more than a third (36%), with a quarter believing GPs (25%) are best placed. These results can be viewed in Figure 17 and Table 39.

Figure 17 Reported Practice of Perioperative ACP

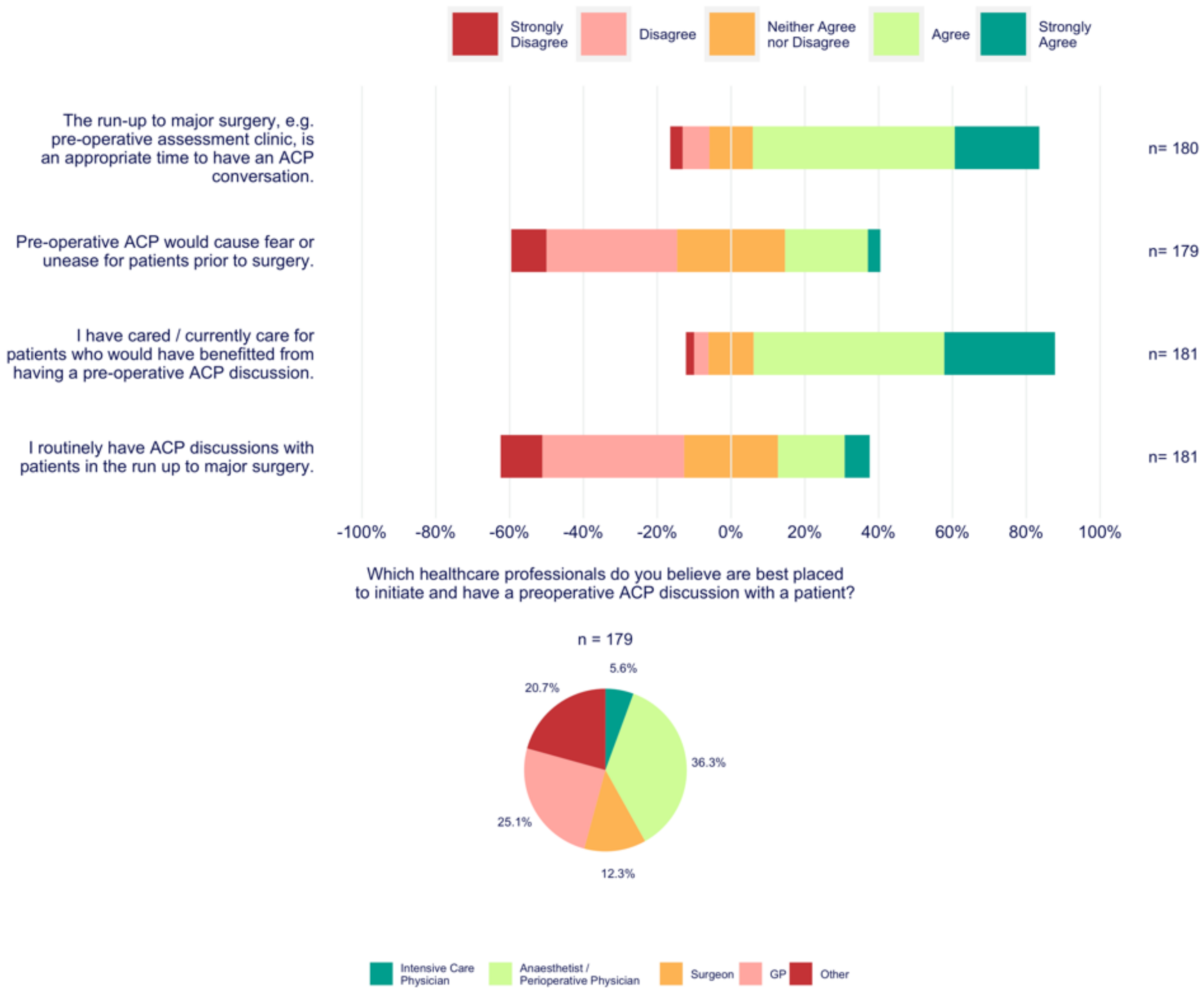


Table 39 Reported Practice of Perioperative ACP

Question	**Strongly Disagree**	**Disagree**	**Neither Agree nor Disagree**	**Agree**	**Strongly Agree**
P6. The run-up to major surgery, e.g. pre-operative assessment clinic, is an appropriate time to have an ACP conversation.	6 (3%)	13 (7%)	21 (12%)	98 (55%)	41 (23%)
P7. Pre-operative ACP would cause fear or unease for patients prior to surgery.	17 (10%)	63 (35%)	52 (29%)	40 (22%)	6 (3%)
P9. I have cared / currently care for patients who would have benefitted from having a pre-operative ACP discussion.	4 (2%)	7 (4%)	22 (12%)	93 (52%)	54 (30%)
P10. I routinely have ACP discussions with patients in the run up to major surgery.	20 (11%)	68 (38%)	45 (25%)	32 (18%)	12 (7%)
	Intensive Care Physician	**Anaesthetist / Perioperative Physician**	**Surgeon**	**GP**	**Other**
P8. Which healthcare professionals do you believe are best placed to initiate and have a pre-operative ACP discussion with a patient?	10 (5%)	65 (36%)	22 (12%)	45 (25%)	37 (21%)

6.3.6 Free Text Answers

Varying numbers of respondents provided comments for each of the questions in the Attitudes and Practice components. The number of comments are presented alongside the summarised themes in Table 40 (Attitudes) and Table 41 (Practice).

When answering the *'general'* free text qualitative question 40 respondents provided a usable answer. The main themes which arose are described in Table 42.

Table 40 Main Free-Text Findings KAP-ACP (Attitudes)

Question	n	Theme	Main issues mentioned in each theme	Illustrative Quotation
A1. ACP should be discussed with every patient when they visit a GP or hospital regardless of how well or unwell they appear.	39	Triaging	There is not enough time, money, or the appropriate skills to complete this for each patient.	*"Inappropriate use of time and provokes unnecessary anxiety e.g. 25-year-old in orthopaedic clinic for knee arthroscopy"*
			For some ACP would be inappropriate because it may cause anxiety or it would lack relevance.	
A2. Most patients are sufficiently informed to make decisions about future treatment options using an advance care plan.	18	Lack of understanding	Most lack understanding of realities of high-intensity medical treatment.	*"Most patients have no idea about what some aspects of healthcare involve e.g. ICU, resuscitation."*
			It is very context dependent.	
			Often not informed about option of no treatment.	
		Doctor as a guide	It is the role of HSCPs to inform and guide patients through these decisions.	*"It is the job of health care professionals to ensure they are aware of the pros and cons of the various options, including not having treatment."*
A3. Most individuals don't want to discuss their wishes about their future healthcare.	14	Not being asked	Feeling that individuals are happy to discuss but are not given the time and space to do so.	*"I don't believe they are being asked to express their opinions to the extent that they should be."*
		Variable	It will depend on the individual, the situation, and who is discussing it with them.	*"Some don't but many do."*
A4. ACP is upsetting for patients and their families.	27	Communication Skills	It can be upsetting if the HSCP is not skilled, sensitive, and honest.	*"Doesn't have to be, but can be if badly handled"*
		Variable	It will depend on the patient, family, and the timing of the conversation.	*"It is upsetting for some and not for others. This is why it takes time."*
		Necessary	Even if upsetting it is a necessary conversation regardless.	*"even if it is upsetting, it is still often the right thing to do"*

A5. It is never acceptable to withhold information about diagnoses, treatments and risks from patients and families.	28	Patient’s choice	It is at the discretion of the patient whether they want the information.	*“The patient can decide how much information they want“*
		Patient vs. family	It is not acceptable to withhold information from patients but may well be from family.	*“Patients - I agree. Relatives - I strongly disagree.*
		Selective	It is not possible to provide information about all possibilities, all risks etc. therefore only the most important / likely should be discussed.	*“Important differentials should be shared where they impact on investigations. Should all possible differentials be shared? No.”*
A6. Patients frequently change their mind about life-sustaining treatment when they are unwell.	22	Variable	Occasionally this can happen, but the impression is that it is infrequent.	*“Some do but it's not frequently”*
		Poor initial discussion	That changing priorities is the result of a poor discussion or lack of serious consideration.	*“They might switch from a flippant comment such as the classic "if I get like that just shoot me" but that hasn't been fully thought out with enough time and information”*
		Well vs. unwell decisions	That decisions made when a patient is well do not reflect their choices when they become unwell.	*“My experience is that many patients want “everything” but feel differently after experiencing ITU for a prolonged time.”*
A7. Health professionals should uphold a patient's wishes to refuse treatment even if it conflicts with their own view.	20	Caveats	The decision should be respected so long as the patient is informed and has capacity. The decision need not be final and can be revisited.	*“if an informed decision”*
		Handing over	If a HSCP feels conflicted, he/she should ‘hand over’ the patient’s care to another who is happy to implement the decision.	*“A better alternative should be that the clinician hands over patient's care to somebody else who is not conflicted”*
A8. An advance care plan is normally too ambiguous for it to be useful to contribute to clinical decisions for a patient who has lost capacity.	18	Quality	If written well then ADs are useful, but if not then they will likely not help.	*“it depends on the ACP, a well written ACP can be very helpful -but usually only if there has been good health professional input”*
		Unknown	Because of a lack of experience of ADs it was not possible to comment.	*“Very rarely, if ever, have come across one”*

A9. I have been in clinical situations where having a documented advance care plan would have been beneficial.	9	Circumstances	Participants mentioned different circumstances in their experience where an AD would have been beneficial.	*“a number of times - especially in cases of emergency care, usually a laparotomy, in elderly patients with many co morbidities and 50:50 chance of survival”*
A10. What is your overall attitude towards ACP?	25	Supportive	Would enhance patient autonomy.	*“This has to be the best way forward to improve patient participation in decisions affecting their healthcare. This will enhance autonomy, make doctors & patients partners”*
			Could improve patient care in emergency situations.	*“Would be very helpful for the on-call anaesthesia team if we knew a patient’s wishes - even if only vaguely written e.g. all care, no ITU, no CPR etc.”*
		Challenges	Participants highlighted challenges that they felt would hinder ACP: patient’s lack of understanding patients and clinicians may be unwilling to have these conversations opinions may change irrelevant for elective surgery may be difficult to interpret if not present at the initial discussion difficult to access info. at times of crisis	*“Although I imagine without medical knowledge can be difficult to imagine circumstances and scenarios”*
				“patients (who often seem unhappy or unwilling to have this conversation) and clinicians (who frequently try to avoid having this conversation or do it poorly)”
				“The quality of a decision is dependent on the quality of information provided when it was made”
				“Where will it be possible for all HCP to access the information and how many items will an Individual ACP be likely to have given it won’t be as binary as a DNAR”
		Conduct of discussion	Participants mentioned the importance of including family as part of the ACP process, that it needs to be frequently revisited and should only happen if the patient wishes it to.	*“It's more than just the ACP - it's the overall discussion with families”*
				“I also think that those who don't want to embark on this should also have their wishes respected”

Table 41 Main Free Text Findings KAP-ACP (Practice)

Question	n	Theme	Main issues mentioned in each theme	Illustrative Quotation
P1. It is my responsibility to discuss ACP with the patients who I see in my day to day practice.	35	Role of anaesthetist	Normally there is no time on the morning of surgery and commonly that is only time an anaesthetist meets a patient.	*"There is no time for this in modern theatre practice unless an ACP already exists"*
			May be inappropriate at short notice prior to surgery. The type of surgery e.g. day surgery, obstetrics may make it less relevant.	*"Not before routine elective surgery. We would not have met the patient before and therefore it is not really appropriate for me as an anaesthetist."*
			There is a lack of the long-term relationship with the patient that is needed to have such a discussion.	*"you need to know the patient and you need time - I don't want the whole burden to fall on already stressed GPs but I don't see that I'm appropriately placed to do this."*
			In some circumstances e.g. emergency it may be appropriate.	*"There are occasions, mainly in specific cohorts of emergency patients, where this is appropriate to be undertaken by the Anaesthetist. Ideally the discussion would be handled by the patient's regular doctor"*
P2. I feel comfortable discussing ACP with patients and those important to them.	11	Challenges	Lack of time.	*"I would if I was properly informed AND had the time to have these discussions"*
			Lack of resources.	*"The hardest thing is often the lack of privacy in hospital settings. There are often quiet rooms for families, but these are rarely suitable for ill patients."*
			Lack of training.	*"I feel the words chosen to do this and some training is required"*

P3. I have sufficient knowledge and training to discuss ACP with patients and those important to them.	14	Challenges	Lack of knowledge of legalities.	*“I'm not entirely clear on the legal footing”*
			Lack of training	*“though i have knowledge, I have no training about ACP”*
			The practicalities of the hospital environment.	*“there are operational and hospital political implications that need addressing before this can be fully implemented; not least the need for more time, upstream of the day of surgery, for discussions with patients and documentation of the same.”*
P4. It would take too much of my time to discuss ACP with a patient.	24	Necessary	Even though time is lacking this is too important to ignore.	*“it is important enough to make the necessary time”*
		Circumstances	It depends on the circumstances of the day and the patient.	*“If pre-op on the morning for day-case ops then too busy. However formal pre-op clinic maybe ok”*
				“depends on the patient's ability to gasp things”
P5. How often do you have any form of ACP discussion with patients?	35	Formality	Respondents mention frequently having discussions about wishes or treatment options but feel this is not ‘formal’ ACP.	*“I do it in a "non-legally binding way", aiming to get an idea of the level of care or specifics a patient would or wouldn’t accept”*
		Role	These discussions may happen when respondents have different roles, i.e. ITU, pre-assessment clinic and emergency surgery but not elective surgery.	*“There is often a form of ACP with ICU admissions/referrals.”*
				“Seldom as an anaesthetist”

P6. The run-up to major surgery, e.g. pre-operative assessment clinic, is an appropriate time to have an ACP conversation.	24	Timing	The discussion should happen as early as possible and not only days prior to surgery.	*"The earlier the better (i.e. soon after moment of contemplation of surgery, not a couple of days before surgery)"*
		Role of the Anaesthetist	These discussions should happen with a clinician who has a longer lasting relationship with the patient.	*"I think this is best done with a clinician who has an enduring relationship with the patient - GP or long term condition specialist"*
		Challenges	Having the conversation close to surgery may be too stressful, induce anxiety, or allow insufficient time for reflection.	*"I suspect absorbing information about all aspects of care when the horizon is full of impending surgery might not have patients thinking as clearly as they might"*
P7. Pre-operative ACP would cause fear or unease for patients prior to surgery.	29	Manner	If conducted carefully and sensitively this should not be an issue. It may even provide reassurance.	*"it would not add to their fear. they have it anyway. it may allow proper preparation and provide reassurance"*
		Fear may be appropriate	Even if the discussions do cause apprehension this may be appropriate for those embarking on high-risk surgery.	*"It might, but this might be appropriate and an opportunity to deal with these things."*
P8. Which healthcare professionals do you believe are best placed to initiate and have a preoperative ACP discussion with a patient?	37	Best placed	The person who has the best training, skills, and opportunity regardless of specialty.	*"Whoever has the appropriate training and skills to be effective"*
		Joint	There needs to be input from multiple specialties to allow sensible decision making.	*"All of the above, ideally in conversation with each other. Seems ridiculous to elevate one over any of the others."*
P9. I have cared / currently care for patients who would have benefitted from having a pre-operative ACP discussion.	3	Hospital Machinery	Without proper discussion and ACP patients can find themselves having treatments they may not want.	*"I have seen many patients been denied the opportunity for pain relief or the ability to say farewell to loved ones due to the paternalistic medical/hospital machinery which has shunted them into theatre to have treatment with poor prospects of survival"*

P10. I routinely have ACP discussions with patients in the run up to major surgery.	12	Challenges	Lack of time or inappropriate circumstances.	*“Normally even for cardiac surgery they are admitted late the night before and the 20 minutes in the morning is not appropriate for this sort of discussion”*
		Triaging	Discussions happen only with a select group of patients.	*“major surgery in very high-risk patients where there may be conflict of patient or family's opinions with medical professionals”*

Table 42 Main Findings from *'General'* Free-Text Question KAP-ACP

Question	**n**	**Theme**	**Main issues mentioned in each theme**	**Illustrative Quotation**
Is there anything else about your understanding of ACP that you would like to share?	40	Challenges	There is a lack of time to adequately have these discussions and no ability to have multiple discussions over time.	*"Shared decision making is time consuming, often takes more than one visit"*
			The documentation of ACP needs to be easily found and communicated amongst HSCPs.	*"We need a national electronic ACP that both clinicians and patients can access and that the patient signs off. Paper just gets lost or isn't available at the time of need/crisis"*
		Timing	The discussion should happen far in advance of patients presenting for surgery and therefore needs to take place in the community by GPs.	*"Timing of the ACP would be best before an operation date is set but that would mean the GP would need to be involved and they often don't feel they have enough relevant information about risks and benefits."*
		Education	Patients need to be well informed and educated.	*"important to be positive when facing major surgery, people also need to have a realistic picture painted for them"*
			More training, particularly about legalities of ACP for HSCPs.	*"I have little understanding of the laws surrounding it but suspect it's unknowingly part of my and many colleagues everyday practice but not recognised as such."*
		Nuances of perioperative ACP	The nature of surgery and the post-operative period necessitates a different approach to issues such as treatment limitation.	*"myself and my consultant were of the opinion (and explained this to the patient) that we would reverse something that occurred acutely intraoperatively. A colleague disagreed with this approach"*
		Negativity	ACPs seem to be inherently focussed on the refusal of treatment.	*"ACP's always seem so negative - the emphasis seems to be about NOT receiving treatment. They almost persuade people that they are a burden."*

6.4 Discussion

The KAP-ACP questionnaire has been developed, validated, and used to describe anaesthetists' knowledge, attitudes, and practice of ACP, including perioperative ACP. This is the first time a KAP has been used on a UK physician population to explore ACP. The findings of this workstream indicate that anaesthetists have good knowledge about legislation surrounding ACP and hold positive attitudes towards it. The workstream has also highlighted particular barriers which may prevent perioperative ACP. These include the timing of the perioperative consultation and nuances of the surgical setting which may make treatment limitations inappropriate.

Knowledge of legislation surrounding ACP did not appear to be a barrier for anaesthetists. In eight out of ten questions a majority of respondents answered correctly. Only one question, K3, was answered incorrectly by a majority of respondents. The only other question which was not answered correctly by a majority of respondents was K6. Feedback was received from one respondent who disagreed with the answer to K6. For this respondent the term *'correct decision'* was interpreted as being synonymous with the patient's *'best interest'*. In such circumstances it was remarked that an LPA/WPA's decision should not be adhered to if it was not perceived to be in the patient's *'best interest'*. The intended meaning of the term *'correct decision'* was to indicate what the healthcare team believed would be the *'correct'* decision for that patient. This may not be in the patient's *'best interest'* if it does not fit with that individual's views, wishes, and priorities. This misinterpretation of the question was not identified during the validation process, but it may partially explain why K6 had a higher level of incorrect answers than other questions.

As in both the SR-pACP and SR-KAP there was broad approval for ACP amongst respondents with 92% either saying they were supportive or very supportive. The vast majority (91%) also report having been in clinical situations where a well-documented AD would have been beneficial. Respondents appeared to support the idea of triaging for ACP discussions with a majority rejecting the idea of having these discussions with every patient. This was both because of a lack of money, time, and staff as well as a fear that it may cause unnecessary anxiety or lack relevance. The concern that the topic could induce fear in patients (231) or take away hope (351) detailed in the SR-pACP and SR-KAP was not widely replicated in the KAP-ACP. The free-text comments did highlight that this was a possibility if it was not handled with sensitivity by the HSCP. It was also remarked that in some cases it may cause upset but would still be the right thing to do. Respondents did not agree with the statement that ADs were often too ambiguous to be useful, although, this was caveated in the free-text comments by saying this may be the case if it has not been well-written. There was particularly strong support for statements which placed importance on patients being well informed and having autonomy over decision making. This is in keeping with findings from the BC workstream which found that these were of key importance when anaesthetists were asked about their own priorities.

Respondents supported the idea that ACP was a responsibility of anaesthetists. There was also broad support for the idea that before major surgery is an appropriate time to have an ACP discussion and over one third believed anaesthetists were best placed to have these discussions. A majority of respondents reported having ACP discussions at least once every 6 months, but only 25% consider perioperative ACP to be part of their routine practice. The free-text comments often focussed on challenges which prevent ACP: lack of time; the timing of consultations; lack of training; and the nuances of the perioperative setting. Half of respondents did not believe a lack of time was a major barrier when directly questioned. Instead, the timing of the consultation was seen as a greater hindrance. ACP discussions on the morning of surgery were felt to be inappropriate as they lacked the opportunity for consideration and reflection. There was little consensus over whether a lack of training prevented respondents from engaging in ACP. Despite the fact that only one third believe that they have had sufficient training, over two thirds feel comfortable having such discussions. A final barrier identified was the nature and nuance of the perioperative period. It was commented that the unique nature of surgery necessitated a different approach to issues such as treatment limitation.

6.4.1 Limitations

This workstream must be considered with its strengths and weaknesses in mind. Despite the content validity process, it is possible that there may have been misreading of certain questions. The fact that a respondent emailed with such a query is evidence of this. As this was an online survey it is possible that respondents when answering *'knowledge'* questions researched the correct answer prior to responding. It may therefore overestimate respondents' knowledge.

The response rate was 34%. This is lower than average response rate of ~38% for online surveys involving HSCPs (269) but in keeping with the average of ~34% for online surveys involving the general population (330). There is a risk of non-response bias given that this is a sub-sample (KAP-ACP respondents) of a sub-sample (BC respondents) of a sub-sample (RCoA-MEP). This was a result of the requirement to only including participants who had given permission to contact them about future work. To address this, respondents' characteristics were compared with known population characteristics. As with the BC workstream the comparison suggested that the sample underrepresented males and overrepresented Consultants. In the case of the KAP-ACP the overrepresentation of Consultants was even greater. This may represent a changing workforce or may reflect actual differences between the workforce and the KAP-ACP sample. Wave analysis was performed which did not reveal a difference between the answers of early, middle, or late responders.

The low Cronbach's alpha scores for the Knowledge (0.4) and Attitudes (0.55) components were disappointing. This measurement of reliability of a questionnaire assumes unidimensionality exists i.e. each question measures the same underlying construct (372). Failure to meet the assumption of unidimensionality will result in inaccurate and misleading estimates of reliability (372). In the case of the Knowledge and Attitude components it is likely that the pre-condition of unidimensionality was not met. ACP is complex and multi-faceted. The KAP-ACP tried to reflect this breadth by asking wide-ranging questions about both knowledge and attitudes towards ACP. In retrospect this likely made it inappropriate to consider Knowledge or Attitudes towards ACP as a single construct and therefore less likely that the scales would show internal consistency. In contrast the Practice component was more focussed. The questions revolved around the idea of whether or not respondents engage in ACP discussions regularly. For example, P5 and P10 both ask how frequently, or routinely, respondents have ACP discussions. This narrower approach with greater repetition of ideas likely explains the higher alpha of the Practice component.

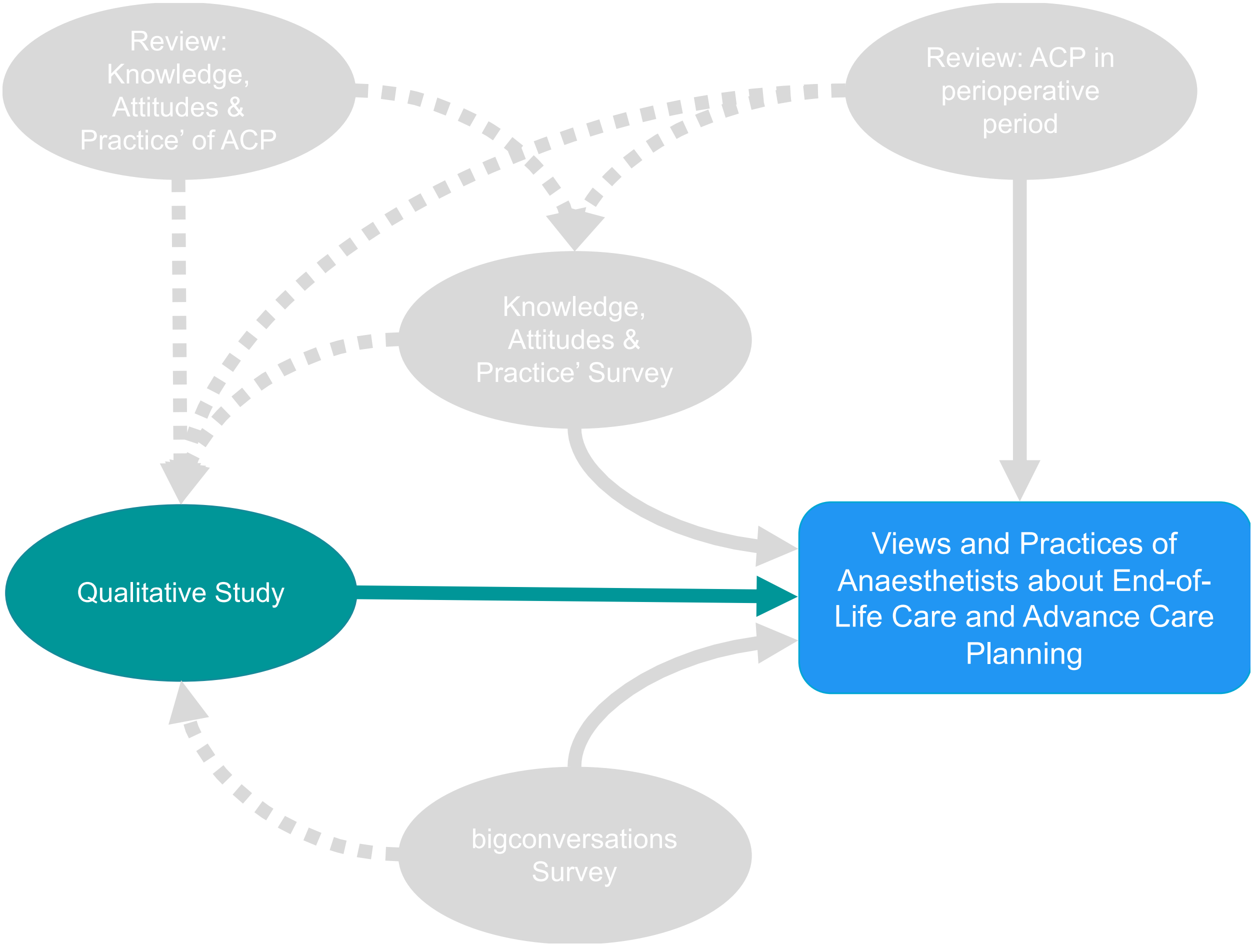
When assessing the effect that this has on the findings of this study it is important to reflect on the following. Internal consistency is a reflection of the questionnaire as a whole and not the individual questions. Low alpha values cast doubt on whether the total (sum) score of the knowledge component is a fair reflection of a respondents' knowledge of ACP. However, responses to the individual questions can be analysed and interpreted individually despite the low alpha. It is for this reason that *'overall'* scores for components in the KAP-ACP have been omitted and only results from individual questions described. The findings have also been extremely useful for highlighting issues which require further investigation in the QSE.

6.5 Conclusion

This study has provided the first systematic description of UK anaesthetists knowledge, attitudes, and practice of ACP. Anaesthetists appear to have good understanding of the legislation surrounding ACP; hold positive attitudes towards the idea of ACP; and feel they have responsibility to perform it within their practice. Despite this, only a quarter report routinely performing ACP in the run-up to major surgery. Concerns that ACP would take too much time or that it would cause fear and anxiety in patients were not widespread. For perioperative ACP greater barriers were felt to be the timing of the consultation prior to surgery and that a different approach to treatment limitations would be required because of the nuances of the surgical setting.

7 Qualitative Study using Ethnographic Methods

7.1 Introduction



The QSE is the final workstream of this thesis and drew on findings from the SR-pACP; SR-KAP; KAP-ACP; and BC workstreams in its design. It aimed to build upon previous results to outline the knowledge, attitudes, and practice of anaesthetists towards ACP and EoL care. Particular attention was paid to potential barriers which may prevent perioperative ACP by anaesthetists.

The SR-pACP identified only one previous qualitative study which had examined these issues (149). This study primarily involved surgeons and originated from the USA. It found that the surgeons felt ADs were generally beneficial but that written ADs often did not match the reality of the situations they faced and that there was a battle between the drive for surgical cure and the treatment limitations often inherent within ADs. Similarly, positive attitudes but concerns about the appropriateness of ACP in the surgical setting were described in the KAP-ACP workstream. The QSE offered the opportunity to explore these ideas in greater depth as well as others highlighted in the KAP-ACP and new topics not raised previously.

7.2 Methods

The reporting of this study conforms to the Standards for Reporting Qualitative Research (SRQR) guidelines (373) as recommended by the EQUATOR network (374).

Within qualitative research there is debate about whether there should be this type of generic quality criteria for qualitative research (375–377). Whilst quality criteria checklists have increased confidence in the validity of qualitative research there is a fear that the diversity of qualitative research means that there is no singular method to measure quality (378). Despite this the SRQR is used when reporting this workstream for two main reasons. Firstly, as a clinician researcher, as opposed to a social sciences researcher with a background in qualitative research, it provided guidance and structure when reporting these findings. Secondly, the ultimate goal of any medical research, including that detailed in this thesis, is to influence practice. The use of reporting guidelines in the medical literature is widespread and allows editors, reviewers, other researchers, and practitioners to critically appraise, apply, and synthesise results (373). Eschewing the use of a reporting guideline, even for good reason, would likely reduce the impact of any findings.

7.2.1 Qualitative Approach

There is no shortage of different methodologies to follow when designing a qualitative study, with some typologies outlining up to 28 approaches (193). The three methodologies discussed most frequently and considered foundational are grounded theory, ethnography, and phenomenology (379). Frequently in the health literature, the approach taken is not specified (202,380)[‡‡] but when it is these are the three methodologies most commonly used (202,381)[§§].

Phenomenology seeks the description of several individuals lived experiences of a concept or phenomenon (193). Grounded theory aims to move beyond simple description and to generate a general explanation (theory) of a process, action, or interaction (193). Finally, ethnography is interested in examining the shared and learned patterns of values, behaviours, beliefs, and language of a culture-sharing group (193). In addition to these traditional approaches, as qualitative research has been adopted more broadly, there has been a growth in the number of studies which, either explicitly or implicitly, are termed generic qualitative research (375). This is research which is not guided by an explicit or established set of philosophical assumptions as per one of the foundational qualitative methodologies (375). These studies can either blend established methodological approaches or eschew a formal methodological framework (379). The goal of these studies remains, like that of all qualitative studies, to understand how people interpret, construct, or make meaning of the world or their experiences (379).

7.2.1.1 Choice of Qualitative Approach for this Study

The qualitative approach chosen is best described as a *generic qualitative study using ethnographic methods*. There are both pragmatic and philosophical justifications for this approach, particularly in relation to health research. Clinical researchers often have good questions which can only be addressed through a qualitative approach (375). This is a result of the inherent complexity of healthcare and the limits of biomedical science to capture the richness and nuance of human health experience (382).

[‡‡] A systematic review of qualitative methods in nursing research between 2008-10 found that 25% of papers did not cite a particular analytic approach. The Yamazaki et.al. review of the characteristics of qualitative studies in the ‘top 5’ medical journals between 2000-04, found 41% did not cite the type of analysis used.

[§§] The Yamazaki review found 49% of qualitative studies used a form of grounded theory, 3% phenomenology and 1% ethnography. A review of research published in scientific nursing journals by Yarcheski et al. found that in 2010 20% of qualitative studies used ethnography, 15% grounded theory and 15% phenomenology.

However, it is rarely feasible for clinical researchers to develop an in-depth understanding of qualitative methodological approaches in order to engage in a deeply theoretical and methodologically sophisticated study (375). Beyond the pragmatic considerations, social researchers and clinical researchers generally have quite different goals. Social scientists' study in order to describe or explain some aspect of human psychology, social relationship, or culture. This requires the adoption of a particular theoretical framework upon which the new research is expected to build upon (382). Clinical researchers tend to study problems in order to solve them (382). It may often be that these research questions do not fit neatly within the bounds of a single established methodology (379). For clinical researchers theories are only useful in terms of whether they make a meaningful contribution to the goal of solving the problem (382). Overattachment to any particular theoretical perspective is to lose sight of that (382).

Percy et al. (383) highlighted three reasons why a generic approach may be best, all of which apply to the QSE. Firstly, generic qualitative research is well suited to mixed methods studies because it allows the qualitative component to be integrated with quantitative results (383). Secondly, generic qualitative research is useful when the researcher has a body of pre-knowledge about the topic and is looking to provide a fuller description (383). Finally, it is useful when the traditional methodologies (phenomenology, grounded theory and ethnography) are inappropriate (383). Use of a traditional approach requires fidelity to its methodology. This might lead away from the topic of which a fuller description is needed or from the quantitative component of a mixed methods study.

It is clear that phenomenology would not be appropriate as the goal of the QSE was not to describe an experience or a phenomenon. Arguably the process of ACP between doctor and patient is one for which a grounded theory approach could be used. However, description and understanding of this process is not the primary focus of this workstream. Rather, the goal is to highlight the views and practices of anaesthetists in regard to ACP.

Ethnography has arisen from the field of anthropology and has been adopted by others, particularly sociologists, over the last century (384). Whilst the theoretical underpinning of anthropology and sociology have changed in that time, the methods of the approach are fundamentally the same (384). Traditional ethnography asks the researcher to, as far as possible, share the environment, problems, language, rituals, and social interactions of a specific group of people (385). It draws on multiple methods including participant observation, in-depth interviews, and serendipitous conversations (384). Ethnography is not prescriptive, but rather a theory about how research should be conducted (384). There are common elements which are included when using an ethnographic approach:

- The design of the study should evolve and change as the study progresses (384).
- The research should be open-ended as the researcher should not enter the situation with pre-planned criteria, or even questions, instead, the research is guided by unfolding events and discoveries (147).
- Fieldwork should take place in *'natural settings'* (386) in the context of participants daily lives (384).
- It should involve direct contact with individuals over a prolonged period (384) observing people in action over time as events unfold (147).
- It respects the complexity of the social world (384).
- It should provide an objective perspective with rich descriptions of people, environments, and interactions (386).
- It should show a bias towards understanding activities from the participant's perspective (386).

Many of these characteristics are present within the QSE, however I did enter the *'field'* with pre-planned criteria and questions and the research did not take place over a prolonged timeframe. Traditional ethnography's focus is the investigation of the network of social groupings, customs, beliefs, and behaviours that define a cultural group (383). The QSE focusses on individuals' reports of their subjective opinions, attitudes, and beliefs about their own experiences of things in the outer world (383). This is perhaps a subtle difference, but it is why the QSE is best classified as generic qualitative research as opposed to ethnography. However, the literature surrounding ethnography, in particular focussed ethnography, has guided much of the design of this workstream.

7.2.2 Reflexivity

A researcher's background and biases will affect all aspects of a study including what is being investigated; the methods for investigation; what results are given greatest prominence; and the framing of conclusions (198). A researcher will always enter a field of research with certain opinions and background knowledge which will influence his/her interpretation of the results (387). Instead of denying any effect of the researcher it should instead be acknowledged, assessed, and shared (198). Bias, in the form of hidden skew, is therefore not eliminated but recognised and accounted for (198). Reflexivity is the tool with which qualitative researchers better represent, legitimise, or question their findings (388). It recognises researcher subjectivity in the research process and focusses on *"how who I am, who I have been, who I think I am, and how I feel affect data collection and analysis"* (388). It has been defined as a *"sensitivity to the ways in which the researcher and the research process have shaped the collected data, including the role of prior assumptions and experience"* (376).

The most important bias that I brought to the research was that of a practicing clinician and anaesthetist within the institution where the research was conducted. The term *'insider ethnography'* or *'ethnography at home'* is sometimes used in order to distinguish ethnography which is undertaken in familiar surroundings to the traditional approach where an ethnographer would travel to far flung and exotic lands (384). Whilst I refrain from calling this study an ethnography the advantages and disadvantages described by using this *'insider'* approach are similar. Some believe that the perspective of an outsider brings an objectivity and allows for speech or actions to be questioned in a way that would simply be ignored or expected by an insider (384). Conversely, insider status can bring advantages such as easier access to areas or people that would normally be restricted to outsiders. Because qualitative research requires access to people, it often requires the finding of one, or more, individuals who will allow the researcher in (a gatekeeper) (193). An insider may be able to dispense with this or may understand who the most useful and interesting individuals are.

A successful qualitative researcher, either insider or outsider, must seek to make the *"strange familiar and the familial strange"* (384). They must constantly question, and both immerse and distance themselves from participants in the process of producing new insights (384). Insider research can be judged by the shock of recognition, the feeling that *"yes, that's the way it is! I had never thought of it that way before"* (147). Throughout my data collection and analysis, I have attempted to look for these new insights.

It was the case that many of my interviews and observations were laced with terminology and phrases which would not have been understood by an outsider. An example of this was during one interview where an anaesthetist was discussing a patient and explained that he was *"worried about her airway"*. An outsider would have needed further explanation as to what this means, whilst I implicitly understood its implications. The anaesthetist was concerned that he may not be able to pass a breathing tube into the patient's lungs or even be able to ventilate the patient with oxygen after she had been anaesthetised. If this is the case the patient may rapidly become starved of oxygen and in a worst-case scenario may die as a direct result of being anaesthetised. This is perhaps the most frightening scenario for anaesthetists and therefore is a cause of grave concern. None of this was discussed between me and the anaesthetist, however, it was all implied in the phrase *"worried about her airway".* Perhaps my translation of this phrase was incorrect. I think this unlikely in this example as the phrase is *'well-worn'* amongst anaesthetists. In other situations where more nuanced terms were used my understanding and the participants may well have been different. From that point the analysis and the interpretation were at risk of bias from my viewpoint and definitions. The requirement of an outsider to ask for a more detailed explanation of what a phrase or sentence meant may have avoided this. However, I could not pretend that I lacked understanding or attempted to ask questions to which I already knew the answer in the hopes of bringing objectivity. To do so would have looked strange and undermined the trust with those being observed or interviewed.

Returning to the example above. The implicit understanding that I shared with my participants allowed a much more rapid exploration of the key topics being researched. An outsider would likely have to spend significant time attempting to understand terminology or the situations being described. This would take up a large portion of interviews or required long explanations during observations even if it was only tangentially related to the research questions. My *'insider'* status allowed that to be, mostly, skipped so the focus could remain where intended.

As an insider I was able act as my own gatekeeper and identify and contact key informants myself. Both my status as an anaesthetist and also that of working within the hospital for a prolonged time meant that I knew most participants prior to interviewing or observing them. Because of this I had few problems with people not wanting to engage or take part. Similarly, when conducting observations, no patients refused to participate. Written consent was not required, as stipulated in UCL ethics approvals, as patients were not the focus of the study and were not subject to any change in their care but verbal consent for my presence was always obtained. When I was introduced to patients it would generally be as *'another doctor and anaesthetist who is conducting research'*. I do not know, but I suspect, that the fact that I was a doctor put patients at ease with my presence as it is not uncommon for a Consultant to have a more junior colleague with them during outpatient consultations. I wonder if a non-clinician presence would have elicited a less favourable response from patients as it may have felt *'odd'* or abnormal.

7.2.3 Context

This study focusses on a relatively narrow aspect of anaesthetic practice which makes it amenable to using the techniques of focussed ethnography. The assumption, particularly in anthropology, is that ethnography is a long-term pursuit, requiring months or years in the *'field'* (389,390). However, in other contexts, such as healthcare and corporate research, the length of engagement with participants has been substituted for intensity (389). In 1988 Scrimshaw and Hurtado *asked "must one spend a year in the field … to make useful recommendations for a health programme?"* (391). The requirement of qualitative health research is that it is able to capture the complex healthcare environment and interplaying social and cultural factors (392) within, often strict, time and budgetary constraints (393). These *'focussed'* or *'rapid ethnographies'* are becoming increasingly used in healthcare (392).

Focussed ethnography takes a more deliberate approach than long term participant observation (389). Traditional ethnographies take a wide-angle view of their participants, where anything and everything that is observed may prove to be valuable

(386). Field notes are written to be inclusive of everything as the focus of the research project may be unknown, or may later change, meaning the significance of the notes are indeterminate at the time of note-taking (386). This rich data set is fertile for future research and investigating longitudinal questions, however, there is clearly an opportunity cost, as energy and effort is expended capturing data which is not useful (386). Focussed ethnographies are characterised by being selective and specific, and focussing on a particular situation, interaction, or activity as opposed to a group or organisation in its entirety (394).

Length of data collection, as is common in traditional ethnographies, is substituted for intensity of data collection (394). Whilst conventional long-term ethnography involves a lot of *'hanging about'* waiting for things to happen, in a focussed ethnography the researcher places him/herself at the centre of the action from the start, and engages participants in the project with clearly stated intentions (389). This requires a sufficiently well-defined research question, focussed observation, and a better selection of informants (386). They are able to address specific aspects of fields in highly specialised groups, but this requires an intimate knowledge of the field to be studied, in order to focus on the relevant topic (394). Judicious selection of the time sample is also important to raise the chances that events of interest will be observed (386).

In my case the focus of the QSE was to answer questions about the knowledge, attitudes, and practice of ACP by anaesthetists. This is a small area of anaesthetic practice. The data from the KAP-ACP presented in Figure 16 indicate that only 36.5% of anaesthetists have more than one of these conversations every six months. Crucial to gathering useful data in a relatively short period of time was identifying the individuals most likely to have these conversations and the locations in which they were most likely to take place. It was also important to seek out the individuals who would care for these patients when the AD may come to be used. The KAP-ACP highlighted that most respondents (53%) did not believe that ACP should be discussed with every patient (Figure 15). The free-text comments suggested that there should be a form of *'triaging'* (Table 40) whereby low-risk patients and procedures are omitted from having these discussions. There was widespread support for having ACP discussions in the run-up to *'major'* surgery in PACs (78%) but concerns were raised that it would be inappropriate to have such discussions on the morning of surgery (Table 41). This is consistent with my own experience and understanding as a practicing anaesthetist and the initial hypothesis outlined in Section 1.3.5.

The QSE was designed to focus on anaesthetists' interactions with patients presenting for *'high-risk'* surgery with a particular emphasis on PACs and those caring for *'high-risk'* patients post-operatively. This was an approach which was very selective in terms of individuals, location, and time in keeping with the principles of focussed ethnography.

7.2.4 Sampling Strategy

The term purposeful, or purposive, sampling is often used in qualitative research to describe how participants, or other information sources, have been selected (395). This term is perhaps a misnomer. All sampling is done with some form of purpose in mind, even random sampling in quantitative research (396). When used it normally describes the selection of *'information rich'* cases for in-depth study. From these the researcher can learn about issues of importance allowing insight and rich understanding (397). Many types of purposive sampling have been described (398) but the common characteristic is that participants are chosen according to pre-determined criteria relevant to a particular research objective (399). These criteria are based on the researcher's practical knowledge of the research area, the available literature, and evidence from the study (400).

Sample adequacy in qualitative inquiry is determined by its appropriateness in terms of composition and size (401). These are important considerations when judging the quality and dependability of qualitative research (373,402).

7.2.4.1 Sample Composition

Section 7.2.3 describes the focus of this study on anaesthetists' interactions with patients presenting for *'high-risk'* surgery. From this a sampling frame was developed. A sampling frame is a criteria for selecting subjects capable of answering the research questions and is used to identify and approach potential participants (403). There were two major components when considering potential subjects: exposure to '*high-risk'* surgical patients and the timing of that exposure (i.e. pre-operative, intra-operative and post-operative). I desired participants who commonly cared for patients with significant surgical risk and did so at different times of their pathway.

One of the commonalities of qualitative research is that the process should be iterative (404). This allows one to add categories during the course of data collection, pursue unexpected links (340), and discover the unexpected (405). The sampling frame was used to guide initial interviews and observations. Some of the most high-risk surgical specialties are Head & Neck, Thoracic, and Urology. These specialties benefited from having dedicated specialty specific PACs which I was able to attend. My initial interviews and observations focussed on anaesthetists who worked in these clinics and those who worked in the ICU looking after these patients post-operatively. Following the initial data collection and analysis sampling was broadened to include individuals and events which had been highlighted as important by participants. An example of this was the inclusion of multi-disciplinary team (MDT) meetings where patients' treatment is discussed by multiple specialities

During data collection the serendipitous opportunity arose to interview a national leader in SDM and perioperative medicine. Although outside the initial sampling framework I felt this participant would add a great deal to my findings and therefore I elected to proceed with interviewing him. The inclusion of participants based on their special expertise is well known in qualitative research and has been termed *'key informant sampling'* (400).

7.2.4.2 Sample Size

Whilst large sample sizes are necessary in quantitative research in order to produce statistically precise estimates, much smaller samples are used in qualitative research (395). Quantitative research values the generalisations to larger populations permitted by large, random, statistically representative samples (406). Qualitative research seeks the *'complexity, depth, variation or context of a phenomena'* (395). The aim of qualitative inquiry is not to acquire a fixed number of participants but to achieve sufficient depth of information in order to fully describe the phenomena being studied (378). A small, non-representative, but highly informed sample can provide rich information (383). There are no a priori power analyses that can be done to determine the minimum number, and kind, of sampling units necessary (406). Patton states *"there* *are no rules for sample size in qualitative inquiry"* (398) and this has led to an ongoing debate within the qualitative community about what sample size is sufficient (406–408).

The most commonly proposed criterion for determining that a sufficient sample size has been reached is *'saturation'* (395). This principle was the most frequently invoked justification of sample size in a review of qualitative health research*** (401). *'Saturation'* originates from the *'theoretical saturation'* used in grounded theory (409). Theoretical saturation refers to when gathering fresh data no longer *sparks* new theoretical insights nor reveals new properties of core theoretical categories (410). This principle of *'saturation'* has since been adopted by other qualitative communities and is often termed *'data-'* or *'thematic-saturation'* (401). This is operationalised as collecting data until no new information is obtained (408). The idea of saturation inherently calls for a *"more is better"* approach as this minimises the chances of codes or themes being missed (411). However, this must be balanced with the time-consuming nature of qualitative analysis. There is also a risk that a sample size too large may preclude the *'deep, case orientated analysis'* at the heart of qualitative inquiry (412).

This idea of saturation is helpful at the conceptual level, however, it provides no practical guidance for estimating sample sizes for robust research prior to data collection (399). For qualitative interviews some authors have provided estimates of appropriate sample sizes based on experts' experience (401) but these can range from 5 to 150 interviews depending on the methodology being used (413).

Guest, Bunce, and Johnson analysed 60 interviews of West-African women examining how they talk about sex and their perceptions of self-report accuracy (399). They found that data saturation had, for the most part, occurred by the 12th interview (399). They did note that their sample was relatively homogenous and that they had focussed research aims. They conceded that a more heterogenous sample with a broader scope would likely require a larger size to achieve saturation (399). Francis et al. (414) presented data from two studies. First, they explored medical practitioners' beliefs with regard to how to treat a patient with a sore throat. They found that they had reached saturation by the 14th interview. Second, they studied attitudes towards genetic testing

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*** Interestingly only 43% of studies provided any justification for the choice of sample size.

of relatives of patients with Paget's disease. In this case they achieved saturation at the 17th interview.

For this study an initial sample of 12 semi-structured interviews was chosen as per Guest, Bunce and Johnson (399). This appeared to be a reasonable baseline given that the population was expected to be homogenous and the research questions were focussed. These initial 12 interviews were analysed with a plan that, should new themes still be emerging, further interviews would be added. Following conclusion of the initial 12 interviews a further 2 interviews (n = 14) were conducted before I was satisfied saturation had been achieved.

Participant observation originated from work by anthropologists and ethnographers (415). Anthropologists often advocate spending at least a year amongst a group because this is a *'natural cycle'* during which most events and rituals will occur (384). As discussed in Section 7.2.1.1 this methodology is being supplemented with the idea of *'focussed'* or *'rapid'* ethnographies. Within this sub-methodology there is little consensus over appropriate study durations with lengths varying between 4 days and 6 months (392,416,417). For studies of shorter duration an *'intensive'* approach may be adopted where a short period of intense data collection is performed over a 1-2 week period (418–420). In the case this workstream I aimed to complete 40 hours (1 working week) of observations alongside conducting interviews. Given that for the most part hospitals run on a weekly schedule this could be considered a *'natural cycle'* which would include most events such as clinics or meetings. The locations were chosen using the sampling frame outlined above. Alongside my interview data I was satisfied that, following 40 hours of participant observation, saturation was achieved.

7.2.5 Data Collection Methods

As discussed in Section 7.2.1.1 the focus of the QSE was of individuals' reports of their subjective opinions, attitudes, and beliefs about their own experiences of things in the outer world (383). Because of this attention to real events and issues it would be inappropriate to use unstructured data collection methods (383). The core focus is external and real-world as opposed to internal and psychological (383). The data therefore must be focussed on this external and real-world experience. This required semi- or structured interviews and activity- / content-specific participant observation (383).

7.2.5.1 Semi-Structured Interviews

Qualitative interviewing is normally classified as being either unstructured, semi-structured, or structured (421). A structured interview often produces quantitative data (421) and these are akin to a survey which is administered face-to-face (384). The KAP-ACP questionnaire (Appendix 7), if administered in person as opposed to online, would represent a structured interview. Semi-structured interviews are in-depth interviews where a participant is asked to answer pre-set open-ended questions (422). They are normally conducted once with each individual and last between 30 minutes and several hours (421).

A key feature of an in-depth interview is that it is designed to combine structure with flexibility (423). Whilst directed by an *'interview guide'* the structure should be sufficiently flexible to allow topics to be discussed in the order most suited to the participant; participant responses to be probed; and the researcher to respond to relevant issues spontaneously raised by the participant (423). The goal is to achieve depth of an answer. An initial answer may be *'surface level'* and will require follow-up questions to obtain a fuller understanding of the participants meaning (423). It should also generate new knowledge or thoughts. It will be likely that the participant directs themselves, or is directed, into considering things they not have explored before (423). This results in deep, nuanced data, which relies on a participant's own language as a way of understanding meaning (423).

7.2.5.2 Participant Observation

Participant observation refers to a *"process of learning through exposure to or involvement in the day-to-day or routine activities of participants"* (424). It is a rather broad term, in that not only does it encapsulate a wide range of observational practices, it is also used to denote a fieldwork strategy which includes general interviewing and the perusal of documents (184). It is the ability of the participant observer to get close to the subjects and to see the world from their perspective which is its chief attraction (184). Participant observation is distinct from direct observation. Direct observation is a quantitative technique in which the observer counts the frequency and/or intensity of behaviours or events (425). The data captured by direct observation are, by definition, those that can be observed and do not require interaction between observer and those being studied (425). Bernard emphasises the necessity of being a *participant* observer when conducting research aimed at describing a cultural group as becoming a participant: allows access to areas from which outsiders would normally be excluded; reduces the risk of reactivity[†††]; and allows the researcher to ask appropriate questions using local vernacular or jargon (415). These reasons were less relevant to me given my *'insider'* status. Indeed Bernard might have termed me as an observing participant; an insider who was observing aspects of life around them (415). My goals during observation were to verify self-reported behaviour described during interviews and the KAP-ACP; to identify unconscious or routine behaviours which often go unreported in interviews or surveys; and to integrate behaviours into their *'real-world'* physical context (425).

7.2.6 Data Collection Instruments

7.2.6.1 Semi-Structured Interviews

The semi-structured interviews were based on an interview guide. An interview guide is a schematic representation of the questions and topics that I wanted to explore (422). It allows the multiple interviews to be systematic and comprehensive and keeps the interview focussed on the desired questions (422).

The interview guide (Appendix 8) was designed using the results of the KAP-ACP and BC workstreams. In particular the free-text component of the KAP-ACP was used to highlight contentious or nuanced issues which could then be explored in greater detail via the interviews.

The interview guide was refined following a *'pilot'* interview as recommended by Creswell (193). General questions about ACP, it's potential or future yielded little more than platitudinous comments. Many of these generic questions about ACP had also been answered using the KAP-ACP survey and I felt there was little to be gained

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[†††] People changing their behavior when they know they are being studied.

repeating this work with a smaller sample size. The more interesting areas of discussion focussed on participants' direct experience. The participants had been sampled because of their roles personally interacting with high-risk surgical and I felt it was this which was likely to generate the most interesting and useful findings.

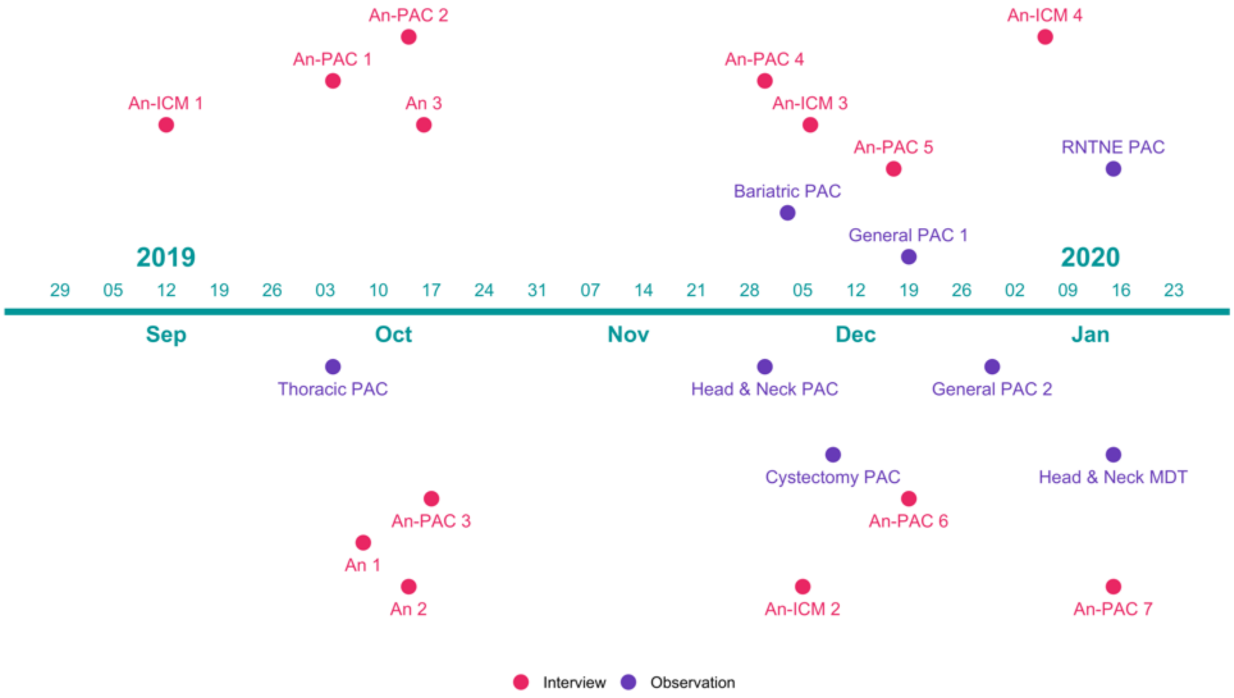
7.2.6.2 Participant Observation

The substance of participant observation comes from keeping systematic, accurate, complete and detailed field notes (426). Fieldnotes are a long established method of data collection in ethnographic research, particularly for observations (423). When conducting observations, I would take mental notes of certain details and impressions, *'headnotes'*, which I would then write down in fuller detail as *'field notes'* normally later that day (427). In addition to these *'headnotes'* I would also record jottings on my phone. Jottings are brief written records of impressions using key words and phrases (427). These jottings were used to help *'jog the memory'* later in the day when attempting to recall details. I aimed to capture examples of language and action, incidents, and conversations which would help me recall the events in detail. When writing my field notes I used a modification of a template presented by Creswell (193) to record both descriptive and reflective notes (Appendix 9).

7.2.7 Units of Study

I included data from 14 interviews and 40 hours of participant observation over a 4-month period. All participants were Consultant Anaesthetists and 13 of the participants worked at the same central London teaching hospital. The 1 participant who worked at a different institution was included because he was a national leader in SDM and perioperative medicine as detailed in section 7.2.4.1. 7 participants had a frequent PAC session as part of their job description (An-PAC). 4 participants, in addition to being anaesthetists, were also intensivists who regularly care for high-risk surgical patients post-operatively (An-ICM). The other three participants had ad-hoc involvement in PAC but were regularly engaged with assessing and anaesthetising high-risk surgical patients (An). Clinics are classified as either being *'General PAC'* where patients from multiple specialties attend, or specialty specific, e.g. Thoracic PAC. I also attended MDT meetings during my observations on the recommendation of participants.

Figure 18 Timeline of Interviews and Observations for Qualitative Study



7.2.8 Data Processing

With the permission of participants interviews were audio recorded. The interviews were transcribed verbatim by a professional transcription company (Essential Secretary Ltd.). The transcripts and fieldnotes from observations were imported to NVivo qualitative data analysis software (Version 12.6; QSR International Pty Ltd.; Melbourne, Australia) for analysis. I chose to use qualitative data analysis software to allow more efficient organisation of the data (428). In comparison with manual analysis the use of analysis software makes it easier to handle large volumes of data; improves rigor by allowing cross-checking of codes; and allows much easier navigation and linking (423). A potential drawback is the way that some software may encourage the tagging and separation of sections of text from their context (423). NVivo allows the linking of coded text to the original interview / observation providing for some mitigation of this risk.

7.2.9 Data Analysis

The qualitative data was analysed using thematic analysis as described by Braun and Clark (299). Thematic analysis offers a process of data analysis which is flexible and compatible with different qualitative approaches (383). It is a method for identifying and displaying patterns (themes) within the data; organising and describing the data set; and can play a role in interpretation and conclusion drawing (299). A theme captures something important about the data in reference to the research question and represents some form of commonly replicated response with the data set (299).

Given that both observations and interviews were conducted by myself I had a good knowledge and familiarity with the data prior to the formal process of analysis. The first phase of analysis involved *immersion* in the data, meaning repeated readings whilst searching for *themes*, as defined above. Upon receiving the transcript of interviews, I would read and re-read these making notes of potential ideas for coding.

Following this I made initial codes that identified basic and fundamental ideas or concepts (299). These initial codes were much narrower than the themes which were to emerge later and were more descriptive than interpretive (299).

Following the completion of data collection and coding further categorisation into themes commenced. This involved the combination of different codes into overarching themes. A thematic map (Figure 19) was created showing the interaction between themes, codes, and other themes (299). Some codes did not fit easily into a particular theme so a separate *miscellaneous* theme was created (299).

I reviewed the collated data extracts for each theme to ensure there was coherence between them. In instances where this was not the case I reviewed the theme and the coded data extracts either moving codes to different themes, creating a new theme, or recoding the data extracts (299). These themes were then assessed in relation to the data set as a whole to ensure that the themes adequately represented the interviews and observations (299). At this point data extracts were coded, or recoded if required, to ensure that they sat within the correct themes and to ensure no data was missing from the final analysis (299). The themes were then clarified, named, and summarised into a coherent account with an accompanying narrative (299).

7.2.10 Techniques to Enhance Trustworthiness

A review of the coding of the dataset, including the cross-checking of codes and the interpretation, was conducted by CVP. CVP reviewed the *'codebook'* and four transcripts of interviews conducted. Following this, minor changes were made to codes and themes with codes added, modified or removed as required to ensure the dataset was coded consistently. This strategy is termed multiple coding and is recommended as a way of reducing the subjectivity of qualitative analysis (429).

7.3 Results

Four broad themes are discussed in depth: *'advance care planning'*; *'go / no-go'*; *'pre-assessment clinic'*; and *'role of the anaesthetist'*. Two smaller themes, which were not encompassed in any of the broad themes, are included in a miscellaneous category: *'emergencies'*; and *'training and experience'*. A summary of these is provided in Table 43 and a thematic map is presented in Figure 19.

The theme *'advance care planning'* explores the low prevalence of perioperative ACP and the reasons for this. There is a concern that opening an ACP discussion pre-surgery may cause unnecessary fear and anxiety for the patient. It would also run counter to the general focus on a positive outcome from surgery which is present from both patients and HSCPs. Additionally, the nature of the perioperative period and the implications of undergoing surgery and anaesthesia mean that discussions revolving around treatment limitations are largely inappropriate. It was felt that if a patient is unsuitable for high-intensity medical treatments then it would likely be inappropriate for the patient to have surgery in the first place. In such circumstances the discussion should revolve around a *'go / no-go'* discussion with this acting as a proxy for decisions about high-intensity medical treatments.

The theme *'go / no-go'* explores the SDM process between patient and anaesthetist when deciding whether or not to proceed with surgery. These discussions involve a combination of ascertaining a patient's goals and explaining risk. This communication of risk happens in a variety of ways depending on the clinician. Patient understanding of risk is also believed to be variable which influences the direction of the discussion.

The structure and organisation of PAC has a huge impact on SDM discussions, and this is explored in the theme *'pre-operative assessment clinic'*. There are multiple roles of PACs: risk assessment; optimisation of co-morbidities and *'flagging up'* of concerns; consent of the patient for anaesthesia and counselling SDM and *'go / no-go'* decisions. It is felt that the focus of PAC is primarily on aspects of physical health and that SDM is less prevalent. Additionally, the time available in PAC is often not sufficient to engage in SDM and is taken up by multiple other tasks. Finally, patients are often not seen until very close to their operation date and this minimises the opportunity to have meaningful discussions.

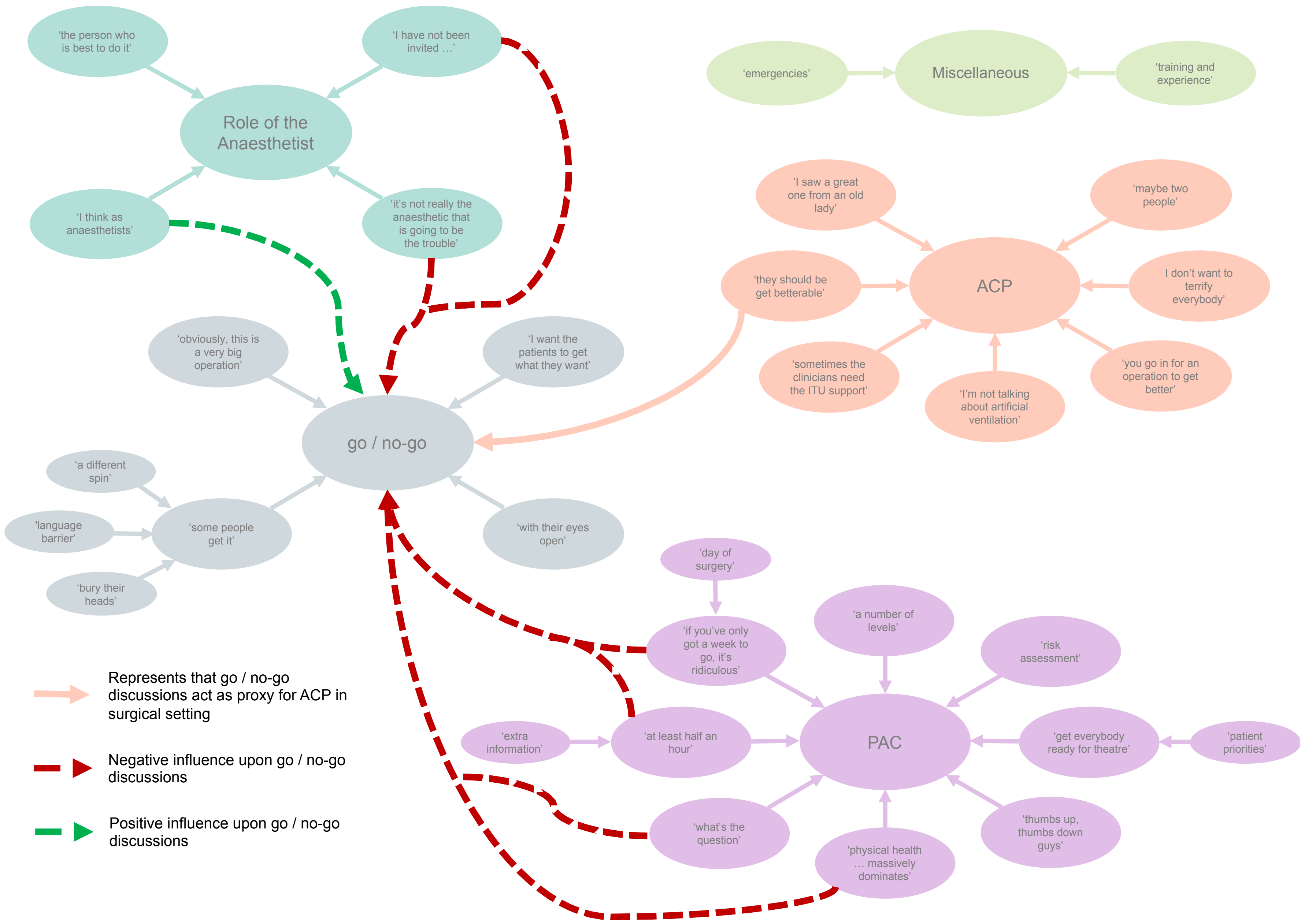
The theme *'role of the anaesthetist'* explores a lack of clarity over the involvement of anaesthetists in SDM. Anaesthetists believe themselves to bring an objective and holistic approach which would be helpful for these discussions. However, a lack of a relationship with the patient and the surgical team as well as not understanding alternative options to surgery can lead a to a reluctance to *'get involved'* in these discussions. This means anaesthetists will often only *'step-in'* if they see something which they believe is very ill-advised. Those who worked in specialist PACs felt this setup alleviated a lot of these concerns and allowed them to become more involved in the decision-making process.

Table 43 Summary of Themes Identified QSE

Theme	Sub-Theme	Description
Advance Care Planning	‘maybe two people’	The rarity of ACP discussions in the perioperative period.
	‘I don’t want to terrify everybody’	The concern that ACP discussions may produce unnecessary fear and anxiety.
	‘you go in for an operation get better’	The focus on positive outcomes from surgery by both the patient and HSCPs.
	‘I’m not talking about artificial ventilation’	The inappropriateness of treatment limitations in the perioperative period.
	‘sometimes the clinicians need the ITU support’	The needs of clinicians to have the ‘backup’ of high-intensity treatments if undertaking high-risk procedures.
	‘they should be get betterable’	The feeling that if an individual is well enough to undergo an operation then they should be well enough for high-intensity medical treatments should they run into complications.
	‘I saw a great one from an old lady’	The attributes of a useful AD.
‘go / no-go’	‘I want the patient to get what they want’	The importance of ascertaining the patients overarching goals when making a ‘go / no-go’ decision.
	‘you would like the patients to come into the procedure with their eyes open’	How risk is communicated to patients.
	‘some people get it’	Whether patients truly understand risk of proceeding with surgery.
	‘a different spin’	How the delivery and emphasis of information impacts patient understanding.
	‘language barrier’	The challenges of language and cultural barriers when having difficult discussions.
	‘want to just bury their head’	Desire for some patients to minimise what they are told.
	‘obviously this is a very big operation’	How go/no-go discussions are introduced to patients.
Pre-Assessment Clinic	‘a number of levels’	The multiple aspects and goals of PAC.
	‘risk assessment’	The role of risk assessment in PAC and how this is performed.
	‘get everybody ready for theatre’	The role of optimisation and consent of patients prior to their operation.
	‘patient priorities’	The role of addressing patient concerns and how these may not always focus on what the clinician deems most important.
	‘thumbs up, thumbs down guys’	The view of PAC held by anaesthetists, other specialties, and patients in relation to go / no-go decisions.
	‘physical health ... massively dominates’	How physical health rather than SDM predominates in PAC.
	‘what’s the question’	The structure of PAC and how this impacts SDM discussions.
	‘at least half an hour’	The expected duration of SDM discussions and how time must be rationed in PAC.
	‘you require some extra information’	The challenges of time management in PAC.
	‘if you’ve only got a week to go, it’s ridiculous’	The timing of PAC in relation to surgery and how this limits its effectiveness as a place for SDM.
	‘day of surgery’	The inappropriateness of having ‘go/no-go’ discussions on the day of an operation.

Role of the Anaesthetist	‘I wasn’t invited ...’	The lack of overall responsibility for patient management that anaesthetists have and how this impacts their willingness to engage in SDM.
	‘it’s not really the anaesthetic that is going to be the trouble’	The *‘ownership’* of risk and how this is felt to lie primarily with the surgeon.
	‘I think as anaesthetists’	The benefits anaesthetists can bring to SDM.
	‘the person who is best to do it’	The role other specialties can and should play in having SDM discussions.
Misc.	‘emergencies’	The differences between having ACP or go / no-go discussions in emergency situations as opposed to elective.
	‘training and experience’	Views over training and experience of clinicians in relation to having these discussions.

Figure 19 Thematic Map QSE



7.3.1 Advance Care Planning

7.3.1.1 ‘I’ve probably only had it with maybe two people’

During my observations I did not witness any examples of an ACP discussion involving EoL wishes or treatment preferences. Respondents agreed that this sort of discussion was not unheard of but is unusual.

> *“I say to them, “Look if you go onto a ventilator, actually you may never come off life support, and what would you want, if you were on prolonged life support?”. I’ve only actually had that conversation with probably two people, because I think those two people were adamant that they wanted surgery and I thought oh my God, they’re really not very fit and I did have that conversation, but this is like probably, two, about a hundred and fifty to two hundred patients, I’ve probably only had it maybe two people.”* (An-PAC 6)

One explanation for this was that patients should have already undergone some form of screening by their surgical team prior to presenting at PAC.

> *“Well it happens rarely I must admit in the pre-assessment clinic because it is a relatively elective setting and so hopefully the patient is able to come to the pre-assessment clinic, they’ve already had like sort of screening from the surgeon who will say maybe you're fit but then we need to do a pre-assessment and speak to an anaesthetist.”* (An 3)

7.3.1.2 'you go in for an operation to get better'

Unlike intensive care, or other settings where ACP may be discussed, in a surgical context, whilst death is a possibility it is not a likely outcome. This is the case for even the highest risk patients. As the *‘damage’* has not yet been done anaesthetists tend to avoid concentrating too heavily on things which are unlikely to occur.

> *“so usually in intensive care the patient is already in a pretty bad state and is already beyond, sometimes beyond the repair and so the conversation is more towards the white or black area so it's easier. In*

> *anaesthetics I think it's different because we haven't performed what may or may not make the patients worse so we are still before this happening and it's like facing this dichotomy and thinking okay you're okay now, you’ve got this operation, it may go this way or it may go really badly, do you really want, and these are the chances that it goes badly versus the chances it goes [well] and then making the risk balance of things. We are prior to inflicting this insult whereas in intensive care the damage has already happened if you know what I mean.”* (An 3)

There is a general expectation from patients that the operation will be successful and will be of benefit.

> *“ I think people really do feel that you go in especially for an operation and an elective operation to get better … with elective surgery that is specifically for improving quality of life, or is a cancer treatment, it is perceived completely differently, and to be faced with someone sort of trying to have a conversation with you know, you do realise that your risk is very high and that you could die, it is, I don’t think that’s why people obviously go in for their operations in the first place, and I think that’s why, that’s a difficult conversation.* (An 1)

This starting assumption, that treatment or surgery is a positive, is also held by the clinicians.

> *“I think as a doctor, I find it you know, you want to be positive, you want to give treatment and you don’t want to sort of be this you know, harbinger of doom.”* (An 1)

This feeds into a general aura of positivity about the outcome for the patient.

> *“when you’re going ahead with a procedure even accepting that there is risk, it’s still very positive, you know, you’re still very much like okay, this is what we’re going to do. Our plan is we want to do this, we want to get you through it. We, you know, yes there are potential*

> *complications, but you, you’re honest about them but you’re still very much like the focus is success at the end of this procedure.”* (An 2)

This positive viewpoint and focus on the likelihood of success is reinforced by the fact that even for the most high-risk procedures most patients will survive.

> *“And the thing is we get away with it most of the time, even high-risk surgery, even surgery with a ten percent mortality, nine times out of ten we sneak away with it. And we ... and you know we're humans and we think in a human scale and you remember the last one who died when you did something, you know but it was a long time ago for most of the stuff we do.”* (An-PAC 2)

7.3.1.3 ‘I don’t want to absolutely terrify everybody’

There is a fear that introducing these conversations would cause unnecessary fear and anxiety for the patient.

> *“it's all a process of consent about they're consenting for having the operation and they need to know what is, a, if it is in any way a likely event that this happens and they need to know about it. But if it's less likely I suppose I don’t go into things in that great detail because I think it is more, I think it's less likely that it's going to happen and you know, I don’t have the time to have that discussion with everybody but also don’t want to absolutely terrify everybody.”* (An-PAC 3)

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> *“I think that [if it is] unlikely to result in a chance of death, so I think to expose them, … to great anxiety and introduce that thought in their mind might be just counter-productive in their overall experience.”* (An-ICM 1)

Associated to this is the idea of maintaining the confidence of the patient in the team that will be looking after him/her.

> *“and in a way I think you do have to have a lot of faith in your surgeon, you know, that’s quite an important idea”* (An-ICM 1)

7.3.1.4 ‘I’m not talking about artificial ventilation if I’ve given propofol and a muscle relaxant’

There is a concern that treatment limitations are simply not appropriate or helpful in a perioperative setting. This is because there is a high-level of cross-over between anaesthesia and high-intensity treatment. It is not clear where one ends and the other begins.

> *“Some people say I do not want to have my life artificially sustained, you know, by machines and mechanical devices. Well, you know any period of post-operative ventilation is artificial life support, isn’t it? There isn’t a number where it says that was post-operative ventilation. This is now artificial life support. We said well that was six hours and suddenly it all changes. All of that, is, you know, is a bit of noradrenaline, you know, life support? Well, yeah. You’d definitely die without it but, you know, we say well they’re on a bit of propofol for their sedation. Their blood pressure’s low anyway. When we wake them up, that will go away … it just doesn’t seem to fit well”* (An-ICM 4)

The reasons for requiring such high-intensity treatments, and the sequalae of them, are also likely to be different than in other settings.

> *“well look if you have one of these little, you know little arrests, we might call them, I don't quite know how best to call them, anaesthetic arrests I'll call them. I think I'd say you should let me, , resuscitate you because I would, because you'll be resuscitatable probably. And you won't ... I guess what you're worried about, as a patient, is that you, you know you get hypoxic brain damage or you get stuck in hospital for the rest of your life.”* (An-PAC 2)

Given the perceived likelihood of success and the fact that the treatments are immediately available, the idea of not providing treatment to a patient was felt to be alien.

> *"And from an anaesthetic perspective I think, you know, if someone's intubated …, for me to anaesthetise a patient, and they arrest on the table, and then not do anything is just like so foreign to me"* (An 2)

7.3.1.5 'sometimes the clinicians need the ITU support'

I was told of the need of clinicians to have access to high-intensity treatments. This allows them to feel supported and be able to take on the risk associated with a major operation.

> *"I think, sometimes the patient says I don't want the support but you should also remember what the clinicians might need as well. So sometimes the clinicians need the ITU support."* (An-PAC 2)

There is clearly a large responsibility on those performing surgery and they may feel the need for the full panoply of high-intensity treatments as backup to support them in case things go wrong. An anaesthetist recounted the following experience.

> *"I had a patient, high-risk patient, a man for a big abdominal reconstruction … He came, he had his operation, he was fine, big operation … So, then he was hypoxic, a bit confused with hypoxia, he got re-intubated ... it didn't seem too desperate to me. Just seemed like a little hump and then he'd get better. His family though said, oh he certainly didn't want long term ITU or ventilation. He wouldn't want to be here being ventilated now, err we think you could just turn everything off now, which they did on the unit actually and he died about 72 hours after his operation. And erm, I'm really sorry about it actually because I, you know, no one likes to flog anyone on the ITU but he hadn't yet got to the point where I think he was being flogged. … So, I'm telling you this story, partly because I think to do high-risk stuff you, the clinician, quite fancy knowing that you have a full back up of the ITU should*

> *things go wrong. Because when you don't have it, it makes you feel like you're slightly less well supported … you know I still feel, oh I would like to have done another 48 hours on the unit before I made that decision."* (An-PAC 2)

7.3.1.6 'they should be get betterable'

There was a broad view that if high-intensity treatments were inappropriate for a patient, then that should be a spur to reconsider proceeding with the operation.

> *"I mean maybe if you thought it was really likely., I mean if you thought it was really likely then maybe you shouldn't be doing whatever it is you were planning to do. That's a funny thing isn't it?* (An-PAC 2)

If surgery is going to proceed it is felt that all treatment options, including high-intensity treatments, should be available to the patient.

> *"yes because I strongly believe that if you're going to, if you're a high-risk patient and you're going to, have surgery then you shouldn't just have half measures to just see how you go, I think that you need to have the best possible chance in order, so that, you can survive and have a good outcome."* (An-PAC 3)

The decision to go ahead with major surgery is therefore seen as a proxy decision for these other high-intensity medical treatments.

> *"if someone seemed fit enough for you to take on the surgery, then, then from my standpoint as the clinician then should they run into problems then you should have thought a bit about that and you know these things should be ... they should be get betterable"* (An-PAC 2)

7.3.1.7 'I saw a great one from an old lady'

Although there was a feeling that treatment limitations would not be appropriate for surgical patients, the idea of using PAC to outline a patient's thought processes and values was thought to be helpful.

> *“I think [PAC] is a good opportunity here to go through the potential list of complications ... some situations that most ... might commonly arise. Most commonly on ICU is the one where they no longer have capacity and putting things in place so that we can effectively manage that patient in line with what they want to do.”* (An-ICM 2)

An experience of a useful AD and what it contained was recounted to me.

> *I saw a great one from an old lady, which was a list of things that she likes doing that ... that she valued as quality of life. So it was going out for walks, looking after her dog and talking with friends. And it said ‘If the doctor looking after me thinks there is no likelihood or a poor chance of me returning to a state where I can do these things, then please don’t let me suffer’. Which was really, really helpful because it gave me a clear goal ... a very clear directive about what ... you know, specifically saying ‘If I thought it wasn’t likely ... ‘and that puts ... not only the burden of decision-making which should be on us, but also gives me something very, very ... you know clear to ... to act on and that was really, really useful”.* (An-ICM 2)

A focus on an ultimate outcome was also felt to be useful in situations where a very rare or unexpected complication occurs.

> *“If you're going to go and have a laparotomy, and you end up having a massive stroke for some reason, no-one probably will have talked about that. They will have talked about a prolonged stay on ICU, maybe inotropes, blood transfusions, maybe a long wean, but perhaps not a stroke. So you may want everything done, because you're having the cancer cut out and you're going to have your Hartman's, but you might not want to live if you've had a stroke, so I think it's quite useful to think of some of the wider aspects of deterioration.”* (An-ICM 3)

Another type of useful AD was felt to be the identification of particular friend or family member.

> *I think the more useful bits of those is when they've nominated someone to help with those decisions … I mean often people have done that implicitly, haven't they? You're dealing with a partner, a child, a mum or a father, , and I think the reason I say that is because … I mean we don't see them that often but the very strict, or the very objective black and white advanced care plans never quite seem to fit the situation. They always seem to be a bit too … they always seem to be an approximation of what you're actually dealing with. So you're start having a conversation with someone as their proxy and that person is still there saying, yeah, but this is not quite what they wrote down" (An-ICM 4)*

7.3.2 'go / no-go'

ACP discussions are uncommon for the reasons described above. When discussions about patient values, wishes, and preferences occur they tend to revolve around *'go / no-go'* decisions for surgery. This decision is viewed as a proxy for all high-intensity treatments. The discussion has two major components: one involves the anaesthetist trying to gather information to understand what the patient's goals and preferences are; the other is the anaesthetist delivering information about the risks of the operation.

7.3.2.1 'I want the patient to get what they want'

Understanding a patient's ultimate goals and whether these are realistic are key to making any decision about surgery.

> *"What do they say? Some people say "I just want six months to spend", whatever it is like "I just want to get to a point where I can attend my son's wedding in six months' time", that's what one person said to me. Another person I think was, it was something to do with family and it was the children that had had, it's usually some significant event that they want to get through to see that, or that they want to go on holiday, one last time to Barbados or whatever it was. So people often realise that it's not, they're not, by the time they get to seventy, eighty, which is kind of the cohort of patients that we have, most of them have thought*

> *about death, and actually if you say to them “It’s a high-risk operation and you might die”, they often say “Well I’m going to die anyway, therefore, I might as well go forward for the operation”. So some of them, most of them, I would probably say like eighty per cent of them say “That’s what I definitely want”, but then there’s like the twenty per cent that are slightly anxious and then they say “Well I don’t want to be in any worse a state, than I am now, I’ve got these symptoms, the most important thing for me is to get rid of these symptoms, because I can’t sleep”. So it depends on what’s important, whatever is important to them, that’s what, but often it’s like symptom control, or it is that they want to get to the next life event for them.”* (An-PAC 6)

Cancer surgery can be particularly challenging for two reasons. Firstly, often, without the surgery the patient will die from their disease.

> *“thoracic pre-assessment it's a bit like normal pre-assessment but someone's holding a revolver to your head … the patients have just got to come and have their operations and they're terrible.”* (An-PAC 2)

Secondly, the speed at which the patient goes from diagnosis to operation leaves little time for reflection.

> *“Particularly I think given that generally the patients that I see are having very major surgery. And because everything has been incredibly fast tracked, because they have cancer they have been kind of taken through a whirlwind of appointments, and maybe not stopped to take a breath and think, is this even the right thing for me.”* (An-PAC 4)

Even in situations where the operation is not life-saving the benefits of proceeding with an operation may outweigh the, sometimes substantial, risk.

> *“If it’s a go/no-go type decision, again, it depends a lot on what the alternatives are, you know. Perhaps the alternative is not going to have much mortality, but the patient’s quality of life will be awful so … She wrote to me recently about, for ICU, some bloke had an awful stoma,*

> *just like terrible high output stoma, so, you know, he should definitely live with a terrible high output stoma. He was not going to have his life saved by having this surgery but he said his life was not worth living. Couldn't leave the house. You know just properly miserable and although he had awful co-morbidity he was quite happy to take his risks of death on the benefit that he might get some resolution from his awful stoma and have a different quality of life in the future."* (An-ICM 4)

Assuming that this part of the discussion leads to a fully informed decision then it may well be appropriate to proceed with surgery even for a very high-risk patient.

> *"I have no problem anaesthetising an extremely high-risk patient, even if I think they're the kind of patient that might die on the table, as long as they understand that. I mean, I think if somebody's totally moribund and there is a sort of 100% chance they're going to die, then I would question the relative merits of doing that. But I think if somebody is extremely high-risk and they may well die on the table or shortly afterwards, if they're desperate for the surgery, and there's a chance we might get them through, as long as they understand that, and that has been discussed, they really understand it, and it's documented, then I'm personally very happy to go ahead and do that."* (An-ICM 3)

7.3.2.2 'you would like the patients to come into the procedure with their eyes open'

To allow a patient to come to such a decision they must be informed of the risk in a way that is understandable to them. It is necessary to deliver this, sometimes upsetting, information whilst trying to avoid unnecessary anxiety.

> *"You don't want to worry them but you don't want them to be shocked by a poor outcome and you would like the patients to come into the procedure with their eyes open as to what the potential complications might be and what the pathway might look like"* (An-PAC 2)

Some anaesthetists will use a scoring system to calculate a numeric risk. These numbers, however, are often adjusted or '*hedged'* when being communicated to the patient.

> *"I might look at the patient and I might say, now you've got some good things going for you or you've got some extra complicating factors that I wasn't able to put into the model. So I might then adjust the number for them and we might then have a discussion about that. But four in a hundred is I think a number that people can think about and particularly when you say, and I don't know if you'll be one of these or not. And that's if I use something like SORT or I might make a bit of more of a guesstimate about what would be the probability if you had a stroke or a heart attack or a serious chest infection. And what's your rate of getting those and did you know that about half of those people might die after the operation. This is for real major surgery we're talking about."* (An-PAC 2)

There is a *"shy[ing] away"* from simply providing numeric values of risk.

> *"I shy away from giving absolute numbers unless they specifically ask; and some patients will and some patients won't."* (An-PAC 3)

This is led by a concern that a numeric value actually doesn't provide meaningful information to the patient.

> *"A one per cent mortality is irrelevant for you, either you live or you die. You don't live one per cent of the time. So what does it really mean other than trying to get some handle on scale."* (An-ICM 4)

So, the anaesthetist will generally try and provide some context to the numbers.

> *"Obviously in this conversation I try to be as objective as possible and also doing some risk calculations and try to quantify the risks, though I tend to quantify the risk in low, medium or high rather than a percentage because I find it easier for the patient to understand"* (An 3)

Additionally, this counselling needs to cover complications which may not result in death but will have significant consequences for the patient.

> *"I will talk about it, if they've already got heart problems or chest problems, so today my lady, I said "Look, one of your biggest problems is the fact that you have a huge risk of having a chest infection, and I'm hoping you won't get a chest infection, but you know the likelihood is that you will", and just to sort of chat to her about the fact that that's going to knock her a bit, it's going to increase her recovery time and, and just really discuss through with that, the implications of that."* (An 1)

7.3.2.3 'some people get it …'

Whether patients understand this risk when it is presented to them is often unclear.

> *"Some do, some don't. Maybe some that I think do, don't, and some that I think haven't got it, do."* (An-PAC 2)

There is felt to be a *"spectrum"* of understanding between patients.

> *"It is difficult and while I wouldn't generalise, it is easier for some people than it is for others and there is a variety of, there is a spectrum so some people get it completely, some people are a little bit in denial and some people just don't have the capacity to understand it either because they are stressed or they just are very, very trustful of the medical profession and say whatever you think is good I will go for it."* (An 3)

The volume and speed at which patients are given information, often at a time when they have been given emotionally upsetting news, is felt to be a challenge to understanding and retaining the information.

> *"In short no, I think they are bombarded by numerous appointments and numerous kind of big chunks of information. Some of which is kind of repetitive in nature, which I think is quite good in terms of coming to terms with the cancer diagnosis is a huge blow, there is always advice*

> *about bring family members, and sometimes writing things down. Because a lot of what is spoken about doesn't … never distils into kind of long-term memory for patients, because they are so blown away by the shock of a cancer diagnosis. So I hope that much of what I say is retained, but I know even on a personal level when I have been spoken to at appointment, you walk out a room, and perhaps you can't remember all the details of what is being said."* (An-PAC 4)

It was described to me that those who are already symptomatic or very unwell may find it easier to understand the risks of surgery.

> *"But they do realise. They're all … those patients are generally incredibly breathless and so they know that they're ill."* (An-PAC 1)

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> *"I think they do understand and I think often patients have a sixth sense when they are really unwell, they feel dreadful and some of them cannot face going through a major, major procedure"* (An-PAC 7)

Some patients may understand that death is a possibility, but it is felt there is a lack of understanding of what dying after surgery entails.

> *"I think we quite frequently bandy the term around, high-risk or moderate risk, and I think when we do that, the average patient thinks well, if I'm moderate risk or high-risk I'm going to die on the table. And the reality is hardly anybody dies on the table."* (An-ICM 3)

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> *"well I'm either going to make it or I'm not, Doc, you know and if I don't, that's fine, you know I've paid my money, I'll take my chances. And that's when I ... I then have to explain to them that's not how it's going to work."* (An-ICM 2)

The realities of death following an operation are generally of a prolonged ICU stay involving multitudes of high-intensity medical treatments.

> *“cardiac surgery is a really interesting one where patients are ... commonly quoted between 1 and 2% chance of death … for having a set of grafts done. What they are not quoted for ... or what’s not explained to them is the morbidity that may occur or what that 1 or 2% chance of death involves or may not involve. And I think that’s the … crux of it. There’s no real appreciation. They believe they’re going to go to sleep and die and there’s a 1 to 2% chance of dying on the table. And when you’ve got a patient who’s stuck in ICU with a tracheostomy and sternal wound break-down, who’s been there for two or three months in and out of delirium, and you’re talking to the relatives and they say ‘Well we never signed up for this’. And that patient’s not hit the 1 or 2% mortality, they’re actually in a broader group who are ... who are undergoing this and that’s something they’re never counselled for.”* (An-ICM 2)

It was felt this is rarely understood and, if it was, it may result in some patients choosing not to go ahead.

> *“I’ve had too many patients tell me if I’d have known what was going to happen I would never have had this. That was for cardiac surgery.”* (An-PAC 1)

7.3.2.3.1 ‘language barrier’

The difficulties in understanding values and communicating risk are even greater when there are language or cultural barriers. I witnessed such a discussion with an Asian lady in her sixties presenting for major cancer surgery. She spoke little English but attended with her two daughters who translated for her. It was difficult to know how much this lady understood because the information, both to- and from- the patient had to pass through a filter.

> *“I think when using a translator, one never knows exactly what has been translated, even if it's a professional translator.”* (An-ICM 3)

The nuances of words and phrases are often lost in these situations.

> *"I think there's a huge amount of nuance, and I think that if one is talking to somebody where English is not their first language, or they're not totally fluent in it, then one has to be a bit more direct, a bit less nuanced, which is then not as nice."* (An-PAC 3)

7.3.2.3.2 'a different spin'

Patient understanding is also dependent not just on what the patient is told but on how the information is delivered.

> *"you can put a different spin on it depending on how you … who you are. Surgeons put a different spin to the anaesthetists to the nurses … Speaking from my own perspective, I really try and, try and be honest but you try and play down as well the one in however many thousand chance of having an epidural hematoma. It's not something you want to labour. You mention it but you don't want to labour it and so I don't."*
> (An-PAC 1)

This *'spin'* may be intentional or not. For example, during my observations I witnessed an occasion where a surgeon had pre-briefed the anaesthetist. The surgeon was not keen on operating on a particular patient because he felt the surgery was unlikely to be successful. Given this, during the consultation greater emphasis was placed on the risks of proceeding to help guide the patient to opt for non-surgical treatment.

7.3.2.3.3 'bury their heads'

Not all patients want to engage in these conversations.

> *"Yeah, it's quite a mixed bag. And I think there are definitely some kinds … of people that want to just bury their head and be slightly walked through a surgical pathway. And there are other people that really want to know about as much as they possibly can, and that then diminishes their anxiety. Where there are definitely some kind of types that they do not want to know very much more than the absolute essential information, and more information is more likely to kind of spook them and raise their anxieties. And it's a difficult one to judge, but I think*

> *sometimes you have to slightly adapt how much or how little you sort of explode information, by getting a sense of that when you talk to the patient.* (An-PAC 4)

When patients prefer not to engage with these discussions, it can be difficult to know whether proceeding with the operation is the correct thing to do.

> *"Yeah, I think you are caught in a bit of a dilemma between wanting to be as transparent as possible, but also respecting what a patient kind of wants of you. And I think some patients signpost very clearly they do not want to be told too much, I think you have to create a very open environment such as, if they do want to ask more questions, … But I think forcing information on people when they have, you know absolutely said that they don't want to know much more than the absolute basics, is tough."* (An-PAC 4)

7.3.2.4 'obviously this is a very big operation'

Anaesthetists develop their own approaches to introducing this discussion with patients.

> *"And certainly now, I think it's over 12 years, I probably have got a bit of a patter, I've probably got some opening ... well, I have got some sort of opening phrases, and some lead-ins which I use"* (An-ICM 3)

When observing anaesthetists, I noted that they would commonly use these individual *'stock phrases'* when discussing issues with different patients. This was the case not only for introducing *'go/no-go'* discussions but for more general matters. One anaesthetist would introduce herself in the same manner to all patients.

> *"I'm … and I'm a Consultant Anaesthetist. It will be me, or someone like me, who anaesthetises you for the operation. Our job today is to make sure you are as good as you possibly can be before we give you your anaesthetic".* (Fieldnotes General PAC 2)

To introduce the *'go/no-go'* component of the consultation, anaesthetists often focussed on the size of the operation and the risk of the patient.

> *“Normally something along the lines of ‘... obviously this is a very big operation. You’ve got a lot of other medical problems. There is a significant risk here”* (An-ICM 2)

I witnessed one anaesthetist using her phone to calculate the risk of a proposed operation in front of the patient. This was despite the fact that she had already done this calculation prior to the consultation. She would stop the consultation and use the phone almost like a prop to say this is what we are going to focus on now. She would then present that risk as, for example, *“3 in 100 people like you who have this operation will die within 30 days”* to the patient. She would then delve into more depth about particular factors about the patient which might make give them a higher or lower risk of dying. She did the same thing for all patients with whom she considered high-risk.

Some anaesthetists described emphasising words such as *‘death’* or *‘dying’* to avoid misinterpretation.

> *“things can go wrong and the worst-case scenario is that you will not survive. I try really, really hard to use the, to actually say the words you may not survive, you may die because I think unless you actually say it, it's very, the skirting around language that lots of us try and use to make it a bit less, unpleasant for people actually means people don’t understand what you're talking about.”* (An-PAC 3)

Another described *“opening a window”* and giving an opportunity for the patient to have the conversation if they wish but not forcing the issue.

> *“I'm looking them in the eye, we're having a man to man. I'm expressing, you know, with my eyes and I'm laying that in because I think it's quite gentle but I think almost, you know, it's not directly, poking the problem, it's me opening a window, we can have this conversation if you want. And I leave it, you know I'll ask it, I'll look them directly in the eyes, and I'll ... there's the window open, you want to come in? They never want to really. And I do ask it quite friendly, you know, I don't, I'm not jumping at them with it.”* (An-PAC 2)

7.3.3 Pre-Assessment Clinics

7.3.3.1 "a number of levels"

The *'go/no-go'* discussions are only one aspect of PAC and there are multiple other functions and roles. Understanding this is important when considering where and when SDM discussions fit in.

> *"I think pre-assessment has a number of different functions. I think that primarily it's a way of weeding out the people who are completely fit and healthy and can pass through the system without too much trouble, to sort of streamline the system. But then to pick out patients who are higher risk, to ensure that they are appropriately investigated, and then appropriately medically managed, so they're optimised for their surgery. I think then it is a ripe opportunity … to discuss the potential risks and the potential postoperative path that they're likely to follow, based on their medical problems and their history."* (An-ICM 3)

These functions, or levels, were often separated into two broad categories: *"kind of [a] clinical level and then a kind of holistic element to it".*

> *"an opportunity to look at the patient both from kind of a hard biological standpoint so how are they going to cope with the actual anaesthetic itself as well as the peri-operative or immediate post-operative period. But also as a chance to take a wider look at that particular patient ... why they've come to a point where they're having this operation; what the decision-making process has been to have that operation; whether or not they are fully informed about what both the operation and the post-operative recover is going to entail and if they understand what the chances in the wider context are for that helping whatever problem it is they originally presented with."* (An-ICM 2)

7.3.3.2 'risk assessment'

Risk assessment is the first function of PAC as its outcome dictates the rest of the consultation. If the patient is felt to be essentially *'fit for surgery'* then the remaining discussion is a consent process and an explanation of *"the normal course of things"*. If it is felt that further tests or investigations are needed, then the plan for this is made and if it is felt that the surgery may not be appropriate then the level of risk is a crucial component of this discussion.

The risk assessment normally starts before the consultation has begun as the anaesthetist will review the patient's notes to have an idea about co-morbidities, the type of operation planned, and other risk factors. This is felt by most to be a combination of *'numbers'* from, for example, a risk scoring system like SORT (Surgical Outcome Risk Tool) or POSSUM (Physiological and Operative Severity Score for the enUmeration of Mortality and Morbidity) and a *'feeling'*.

> *"It's probably a combination of both. Certainly the numbers will make me start to think like that but sometimes the feeling from the patient"*
>
> (An-ICM 2)

For one anaesthetist, within his opening conversation with a patient he would ask how they travelled to the hospital for the appointment. This was not just idle chit chat to relax the patient. It was, for him, a crucial part of his risk assessment. He explained that whilst he did use the SORT score on some occasions in his view if a patient had managed to travel to the hospital using public transport, they had shown that they had sufficient fitness to survive an anaesthetic. During that clinic I witnessed two contrasting patients. The first, a lady in her sixties, appeared cachectic and had a history of a prolonged ICU stay following her last operation. She did however arrive at the hospital independently by taking two busses. The next patient was a lady in her forties who had arrived in a wheelchair via hospital transport. She arguably had fewer co-morbidities and was younger than the previous patient. Whilst the first patient was to proceed to have her operation the second was referred for another investigation prior to further review. It would be wrong to suggest that participants were dismissive of scoring systems but rather that they were felt to be insufficient if used alone.

> *"there is a difference, partly because I think the risk assessment tools are pretty good where you're having straightforward, first time elective surgery. But a lot of the things that actually make us scratch our head is*

> *where people are having one off operations, you know big revisional surgery and then it's quite hard, even though you put in major complex … in fact it's not really well describing what's going to happen."* (An-PAC 2)

This view that clinical judgement was crucial was widely shared.

> *"But some of it is also just about looking at the patient, isn't it? So there may be people who look good on paper, but who look terrible in person, and vice versa. So it's a combination of those factors."* (An-ICM 3)

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> *"I should say risk scoring system and everything else but in real life it's looking at the operation and the patient and their comorbidities and the holistic view of the likely outcome from a patient with loads of comorbidities having that surgery. I think that there is a role for … scoring systems… but, ultimately I think there is still a lot of clinician led experience that needs to, that needs to happen in terms of the integration of patient comorbidities with operations."* (An-PAC 3)

Another case I witnessed involved a lady in her seventies who was presenting prior to a hysteroscopy. The anaesthetist spent quite a long period reviewing her notes prior to the consultation. She appeared to be very high-risk with a recent admission to hospital following an episode of irregular heart rhythm and heart failure. Prior to her appointment, the patient had actually walked into the consulting room by mistake and the anaesthetist had commented to me that *"she actually looks quite good"*. When the consultation did begin it became clear that she was recovering very well from her recent admission and was relatively healthy. There was an opportunity to proceed with her operation after titrating her medications and altering the anaesthetic plan.

I witnessed a contrast to this focus on risk assessment in PAC when I attended a MDT meeting. This was a large meeting where I counted 36 individuals when I entered the room. It was comprised of multiple specialties: surgeons, radiologists, and oncologists, all clustering together in their specialty groups, as well as a sole pathologist. The MDT was focussed on the patient’s disease: type, location, spread, and possible treatments. There was little discussion of patient fitness or co-morbidities. Occasionally somebody would mention *‘performance status*’ but this would frequently be the only reference to fitness. One of the cases discussed did elicit a more in-depth discussion about risk and benefit following an interjection from an anaesthetist. This was a young man with two significant genetic disorders. These ruled out radiotherapy as an option meaning his only potentially curative option would be to have an extensive and major operation. We were informed that he had been discussed at his parent specialty’s (Haematology) MDT who felt he should be treated no differently than a patient without his genetic conditions. This seemed to his primary surgeon to be a green light to proceed. One of the anaesthetists raised concerns at this point by saying that he was clearly at significant risk perioperatively given his medical conditions. There was a question of his long-term survival if he were to be fortunate enough to have a curative procedure. His prognosis without surgery was thought to be around 1 year. There were also concerns raised by other surgeons about the technical feasibility of the operation. The primary surgeon admitted that he had not had a discussion with him yet about what the patient would choose. This was the only occasion where such a discussion occurred, and it seemed to do so only because of the glaring nature of this young man’s medical diagnoses. There was no such risk stratification or discussion about patients who may have been elderly or have multiple co-morbidities.

7.3.3.3 “get everybody ready for theatre”

As a corollary of risk assessment there may be an opportunity to *‘optimise’* the patient i.e. treat or improve a comorbidity so that it reduces the risk of surgery.

> *“optimise the patient to make it as safe as possible”* (An-PAC 7)

PAC commonly:

> *“identifies and quite often makes new diagnosis of medical problems that might be important for the patient.”* (An-PAC 2)

These diagnoses may have benefits beyond the operative period.

> *"let's say for example the hypertensive, this [diagnosis] is going to help with their outcome in life, not just getting them ready for the operation if we can treat it, if we pick it up and treat it."* (An 2)

The goal of this was described to me:

> *"I would feel that that's part of my job is to highlight things so that the team on the day feel as prepared as possible as well and they're not going to get any sort of nasty surprises."* (An-PAC 7)

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> *"You're not going to be that same anaesthetist and that anaesthetist is likely expect a certain set of work to be done so they can go ahead and do the work, so some of it is kind of investigation planning and management."* (An-ICM 4)

7.3.3.3.1 'patient priorities'

Alongside the medical role of investigation and optimisation, there is also a psychological role informing the patient of what to expect and answering any questions:

> *"explaining to the patient what's going to happen and try and give them some impression of what the normal course of things would be."* (An-PAC 2)

This role of consenting and explaining the *"normal course of things"* was infrequently mentioned during my interviews however it formed a large part of the consultations that I observed. One consultation I witnessed involved a lady in her seventies presenting for major surgery. She was a high-risk patient, yet her main worry was cannulation. She had *'small veins'* and when attending for a CT scan a student nurse had required 6 attempts in order to cannulate her. This clearly worried her, and it took some time to reassure her that this would not be an issue when she came in for her operation. Addressing this concern took considerable time and accounted for a large part of the consultation. It was important to relieve her of this anxiety however it prevented perhaps more important discussion about her risk of major complications or even death. This was an example of how patient concerns may not be aligned to that of HSCPs.

7.3.3.4 'thumb up, thumb down guys'

It was described that some patients viewed PAC and the anaesthetist as the decision maker over whether the operation can go ahead.

> *"they sort of think that you, the anaesthetist, say yes or no whether you can have the operation and ... not all of them, but a lot of them do"* (An-PAC 2)

It was felt that this view was sometimes shared by surgical colleagues.

> *"I think sometimes anaesthetists and pre-assessment are seen as the grim reapers of obstacles to the surgery doing what they want to do."* (An-PAC 7)

However, among the anaesthetists I interviewed there was resistance to the idea that PAC should be a *"gatekeeper"* for surgical treatment, although it was felt that it should *"feed in"* to these decisions.

> *"Not primarily. I think that should already happen like in the surgical clinics but they should, but sometimes there are some cases that are not clear cut, like it's easy when everything is straightforward, like when the patient is having a minor operation it is easy when it's very, very high-risk, having very, very high-risk surgery then black or white it's easy to make these decisions and then there is all this grey area. So that is I think where I think our role as consultants for the surgeons can be valuable because we just add on an element but I don't see, I don't see ourselves as being the thumb up, thumb down guys, we are the ones who can provide extra information and extra elements for then the surgeon to understand maybe it's not for this patient or even for the patient to understand maybe it's not really what I want."* (An 3)

Attending another MDT meeting I witnessed a good example of this type of collaborative decision making. The anaesthetist presented a patient who he described as *'high-risk'* for surgery but caveated this by saying that if the consensus amongst others (surgeon, dietician, physician, and psychologist) was that this would be the best treatment then surgery could proceed. The decision from the MDT was that the patient should not be offered surgery at this time but instead be referred for medical management.

> *"they [surgeons] might be weak advocates, they might say, well the surgery is going to be difficult, they've had previous operations. And then the dietician might say well actually their current diet is terrible and they've got poor dietary understanding and if they don't stop drinking five litres of coke a day before we do the surgery it will all be for nothing. And then I might put my hand up and say they've got very poorly controlled atrial fibrillation and the medic might say, yeah, the diabetes is terrible too. And then ... so now you've got ... which on their own each one of these might be a, you know, a minor flag and if everyone else in the room was saying no, no it's alright from where I sit. Then you'll take that patient through for an operation. But if little flags go up in all corners or enough corners of the room, then obviously everyone says, oh this is ... err this might not actually be in the benefit of the patient."* (An-PAC 2)

Whilst the *"thumb up, thumb down"* role was generally rejected, the counselling role described above (Section 7.3.2) is considered to be a part of PAC.

> *"Occasionally, but less often, there is a sort of a counselling go/don't go type of decision making where you kind of look at the procedure that's being proposed, the patient's set of co-morbidities and just think the two things aren't compatible, and you just wonder what conversation's actually been had in the surgical clinic."* (An-ICM 4)

It was felt PAC offered an opportunity for this to happen.

> *"I think pre-assessment clinic, especially for truly elective stuff, you really do have time, even though the pressure might be on, and there might be waiting lists, but you really do have time to make sure that you're doing what you think is right for the patient. And for, and there's time for the patient to sort of assimilate all this information, and make a decision for themselves."* (An 2)

And that this should mean that patients are prepared psychologically and have made a truly informed decision by the time surgery proceeds.

> *"Someone who's come through pre-assessment clinic, they've had time to think about I guess ultimately if they want to have the procedure. You know they've, truly informed consent, they've had time to, with all the risks, if there are any risks, they've had time to weigh them all up. Had discussions with the relevant clinicians."* (An 2)

7.3.3.5 'physical health … massively dominates'

Despite the stated importance of the SDM aspect of PAC it was generally believed to be secondary to the *"biomedical stuff"*.

> *"I think the practicality of what happens is, it's all about the streamlining patients to get them through, and it's about sort of biomedical stuff."* (An-ICM 3)

This was lamented and felt to be a missed opportunity.

> *"the physical health and making sure that patients are fit for surgery massively dominates erm and I think it's a shame, I think we'd actually be better if we had longer to spend with higher risk patients discussing what they're like, what their desired outcome from surgery was and whether or not they should go ahead."* (An-PAC 3)

It was suggested that the ethos of PAC is not one which is focused on SDM as a primary goal.

> *“I think pre-assessment would need to … have a different ethos I think. It would need to be moved away from ... the slightly more biological bent onto thinking about these things. And it would also need to be a longer and more involved process than ... you know, we have time to deliver at the moment. At the moment it’s about getting the patient through the operation, not necessarily about increasing their overall quality of life which is of course what it should be about.”* (An-ICM 2)

I was told that the origins of PAC were in the 1980’s and 90’s with a drive to determine patient suitability for on the day of surgery admissions.

> *“the pre-assessment sees its role as making sure there are no on the day cancellations and that it's driving, a sort of ethos within the hospital. They are, they're given funding, you know they exist by the very nature of stopping on the day cancellations”* (An-PAC 3)

This may be the current institutional drive for PAC but there would likely be advantages for the Trust in avoiding surgery for high-risk patients *“lead[ing] to a massive cost reduction because they're [the patient] not spending months in intensive care.”* It was felt that it is extremely difficult to measure this sort of impact and this explains the lack of focus on SDM.

> *“I suppose it's very difficult to quantify because it's very difficult to quantify the benefits to a person’s life if they decide not to have surgery, it's very difficult to quantify that as a success for the hospital if someone decided not to go ahead with the surgery even if that is ultimately what is probably better for them. So I think it's, I think until there are measurable metrics by which we can demonstrate this is a good outcome I think it’ll be very hard to be given the time, the funding and the infrastructure needed in order to be able to have longer shared decision-making consultations with high-risk patients.”* (An-PAC 3)

This ethos and focus on the *‘biomedical’* filters down to all aspects of PAC affecting the structure, organisation, and timing of these clinics.

7.3.3.6 ‘what’s the question?’

PAC operates by using a triage system. Not all patients will be seen by an anaesthetist. The majority will be reviewed by a pre-assessment nurse and deemed fit for surgery. A smaller number will be triaged for a *‘notes review’* and an even smaller number will be referred for a *‘face-to-face’*.

> *“it's probably resourcing the patients who are those patients I was talking about that you know, are high comorbidities, high-risk surgery so it's channelling the expertise into those groups of patients to try and make sure the right decisions are made and that they're optimised adequately. So the triaging is very, very important because obviously anaesthetists in the funding situation absolutely cannot see every single patient that’s you know, never going to happen but you do need to have a system whereby hopefully there are alarm bells or protocols in place or whatever or the pre-assessment nurses feel confident.”* (An-PAC 7)

During my observations there was a mixture of *‘notes reviews’* and *‘face-to-face’* consultations although notes reviews took up slightly more time. A notes review is when a PAC nurse has identified an issue or concern about a patient, e.g. an abnormal ECG, and requires an anaesthetist’s opinion prior to declaring the patient fit for surgery. The patient will not be seen by the anaesthetist but rather the notes or investigation will be evaluated, and a decision made. Clearly a *‘notes review’* does not lend itself to any form of SDM given that the anaesthetist will not see the patient.

A *‘face-to-face’* consultation occurs when the nursing staff have greater concerns and feel that the patient should be physically seen by an anaesthetist. For high-risk surgeries like major head and neck there was a lower threshold for being referred for a '*face-to-face'* consultation.

> *"we are in a slightly more privileged position that we get face-to-face appointments with each patient, and these patients are almost always undergoing very major surgery."* (An-PAC 4)

When nursing staff make a referral for a *'notes review'* or a *'face-to-face'* they do so in the form of a *'question'*. This question is a variant of *'can the operation go ahead given X?'*. This was evident in a consultation I witnessed with a lady in her sixties presenting for major surgery in the following two weeks. She had no documented co-morbidities but appeared frail and the two anaesthetists present agreed, following the consultation, she was high-risk. They also questioned why she had been referred to see them in the first place, *"what was the question?"*. Despite this patient being acknowledged as high-risk there was no specific issue which would preclude the operation going ahead. Given this, there can be confusion over what role the anaesthetist should play in this situation.

This structure of PAC is that it is essentially a nurse-led clinic with the anaesthetist being available to *'troubleshoot'*. On two occasions when I attended to observe a clinic there was no room assigned to the anaesthetist. We either had to find a space that was unused or *'borrow'* a nurse's consultation room when a patient needed to be seen. The reason for this was that whilst the nurse-led clinic would run each day, an anaesthetist would only be available for a day or half a day during the week. It would therefore be a *'waste'* of a room if it were to be left empty for most of the week. It is clearly a barrier to engaging in an in-depth and difficult conversation if you lack the appropriate space to do so. On occasions where a room was available interruptions were common. Nurses often come in to ask the anaesthetist questions and try and quickly *'close out'* issues. This is often because a patient is having surgery within one or two days and an answer is needed urgently or to confirm whether a patient needs to wait to be seen *'face-to-face'* or can go home.

7.3.3.7 'at least half an hour'

A particular challenge to having any SDM conversation is their length.

> *"Slowly I think, most of the time. I think that's something you feel isn't always recognised by others. Those conversations take time to have, not just time for the actual time you're allocated to this particular conversation, but just to get to know someone and sometimes you feel that there's an external set of pressures to deliver signed and sealed decisions right up front in a very early stage but you don't know people and they don't know you and they don't know the situation and it just takes some sort of time to get to know people about where things are."* (An-ICM 4)

Half an hour was the minimum these conversations were felt to take, with it often taking longer.

> *"At least half an hour, and, because I think it takes that long for you to be able to gauge enough, their medical history and then delve a bit more into what their hopes and expectations are for having an operation or not and to gain a rapport with them so that you can honestly find out what they are, what they want. I think less than that is just ridiculous and I think many cases you end up spending more time than that with a particularly difficult one, because it's very difficult to have a conversation when you're telling a patient that they may die, you can't just; right you're in, that's your medical history, you might die, what you want me to do about it."* (An-PAC 3)

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> *"To give really informed and all the elements I think in pre-assessment certainly half an hour to an hour"* (An 3)

One particular clinic I witnessed involved patients presenting for the same large cancer operation. These patients had already had their medical histories well detailed and investigations performed so the medical assessment and optimisation component of PAC was relatively small. A much greater time was spent on the *'go/no-go'* discussion.

Each of these consultations lasted over 45 minutes and despite one patient not attending, the clinic overran by nearly an hour.

7.3.3.7.1 *‘you require some extra information’*

Other tasks in PAC are often very labour intensive and take significant time. Both *‘notes’* or *‘face-to-face’* reviews often involve a search for further information.

> *“you might have to say look I need to liaise with your cardiologist, I need to do some more tests to be able to give you a more informed risk of what's going on.”* (An-PAC 7)

An example of this involved a *‘notes review’* for a patient with a clotting abnormality who was presenting for a minor procedure. Trying to *‘solve’* this issue required discussing the case with a Haematologist for advice. This involved multiple *‘bleeps’* to a Haematology Registrar who was initially unavailable. When the anaesthetist was eventually able to get a response, the Registrar wanted to discuss the case with her Consultant. A plan was finalised towards the end of the clinic, but the process involved multiple conversations and significant time.

This workload has to be picked up either during the clinic or by another anaesthetist at a clinic on a later date. Similarly, a *‘face-to-face’* is normally preceded by a period of *‘digging’* for information to help inform the consultation.

> *“so I make, I try to, before I see the patient I try to get as full a picture of the patient as possible so that I can tell them what I understand by what's happened to them in the past so that they gain trust that I am interested in them as opposed to, asking the same set of questions that everyone else has asked them.”* (An-PAC 3)

During my observations a 75-year-old gentleman, presenting for a wrist operation, was referred for a *‘face-to-face’* as he had recently had a five day stay in ICU following an unrelated surgery. It was clearly crucial to understand the nature of this ICU stay to help determine the risk of proceeding with the operation and steps which could be taken to mitigate these. The anaesthetist spent time reviewing both electronic and paper notes. This took a considerable amount of time as even within a comprehensive electronic records system the information is often fragmented. It involved reviewing multiple notes entries at different times and trying to piece together a picture of what happened. This is even more challenging if the information resides in older paper notes or in a different hospital.

> *"we may not have all the information when they actually come in because we haven't got time to do further investigations and when they come in we haven't got all the results. We haven't got blood tests, we haven't got … we haven't always got all the information from the district general hospitals and part of that issue is that it doesn't come as a package, they're not all computerised … We often have to ring back and ask for extra investigations, information."* (An-PAC 1)

The time spent performing this aspect of the role minimises the opportunity to have in-depth discussions with patients. Additionally, as all of the necessary information is not immediately available it limits the ability to have discussions with patients who are seen face-to-face. If you are awaiting information from an investigation or from a specialty review it may not be possible to explain to a patient how '*risky'* the operation is and therefore whether it is appropriate to go ahead.

7.3.3.8 'if you've only got a week to go, it's ridiculous'

It is not only the time available but also the timing of the consultation which has a large baring on what can be achieved at PAC.

> *"for every aspect of pre-assessment the pathway is not ideal, if you want to optimise somebody, if you want to have a proper conversation about whether or not to go ahead doing it after the operation date's been set if you've only got a week to go it's ridiculous"* (An-PAC 3)

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> *"I do frequently feel that we are seeing the patients so late in the day in their kind of peri-operative pathway. For example, this clinic runs on a Friday, and the major surgery patients whom I frequently see are having their operation on Monday or Tuesday. So, there are zero*

> *working days to even have an email dialogue with a colleague, let alone request further input tests time for the patients to think about things. So, the pre-assessment kind of moment of care comes very late, and I think that's sometimes a bit of a handicap."* (An-PAC 4)

Traditionally, PAC is not regarded as part of the decision-making process.

> *"it used to be you couldn't be booked for pre-assessment until you had a date for surgery. It was like a ... you know if you didn't have a date you couldn't come."* (An-PAC 2)

Even though that is not the case now the vast majority of patients will have been given a date for their operation.

> *"often they've been given a date for surgery, so it's fixed in their mind that they are having surgery and they've made up their mind they're having surgery"* (An-PAC 1)

Cancelling, or even delaying, the operation at this point would be a surprise and viewed as something going wrong.

> *"So I suppose it's almost they're on an inevitable path towards having an operation and to put a break on things because they've received a letter from the hospital telling them what the operation date is going to be and they, most patients absolutely believe that that is set in stone and there's no wriggle room and if they can't have it that date it's an absolute total disaster"* (An-PAC 3)

The SDM aspect of PAC is often one which is not well understood by the patient.

> *"Fifty fifty about whether or not they think that what I do, often they just say "You're going to go and see the Anaesthetist after Preassessment to see if you're fit" and they don't really know what that conversation is about or who I, some of them, most of them know that you put people to sleep, so they know an Anaesthetist puts people to sleep but whether or not they think that your job role is to have a risk conversation with*

> *them or to help them to make a decision about surgery, I don't think that that's on their radar."* (An-PAC 6)

This makes the discussion itself much more challenging.

> *"We don't think that they come in with an expectation of being told that they maybe should think again about surgery if they're very high-risk. They're certainly not … I wouldn't be expecting that.. So, sometimes when we've had to do that, it's a bit more traumatic."* (An-PAC 1)

This creates a real difficulty for the anaesthetist when they feel proceeding with the operation may not be the best decision. It can mean that they will only involve themselves in the most extreme cases.

> *"It's almost a fait accompli. This patient's coming for an anaesthetic and by the time I flag it up, it's because we're getting very close to go time and I've spotted that I think this is a seriously ... there's a serious problem and this is a really terrible idea"* (An-ICM 2)

There is a concern of how this will impact, and be viewed, by both the patient and the surgical team.

> *"I think sometimes we are a little bit late to the party on joining these discussions. And I think it can possibly lack a little bit joined up care from the patient's perspective if they have been to numerous appointments, where for example a major operation is being talked about and planned. And then they see an anaesthetist who then sort of says, hold on do you really want this, have you thought about something else … you don't want to step on the toes of your colleagues, or similarly kind of lose the trust of the patient and their family that they are having the surgeons and the surgical teams that they work with. You know you can't be a bull in a china shop and just kind of sort of spoil the preparations that have been done so far. And I think the problem with that is that in pre-assessment we are the very last sort of stop in this long train ride through to surgery. So it*

> *sometimes feels a little bit less than reassuring to the patient that you are kind of moving the goalposts a bit, and what is often a very final point for them."* (An-PAC 4)

In cases, where anaesthetists are involved earlier there is a feeling that they can become more involved in this decision-making process.

> *"when it works nicely the surgeons know when they get patients through who are high-risk for the procedures that they're going to do. And then they contact us before, or they'll send you something cryptic about can you, you know, just check this one over because we're considering doing some big abdominal operation. Erm, and in that case that's quite nice. Then it feels like you are actually part of the process and being asked to, erm help in the decision-making for the patient and the team. So when you get sent patients specifically for you to assess them and to feedback to the team as part of an ongoing discussion, much more like an MDT is."* (An-PAC 2)

7.3.3.8.1 'day of surgery'

The idea of having a *'go/no-go'* discussion on the morning of surgery was generally disregarded.

> *"By the time you've got to the day of surgery I think it's a waste of time. I think everyone's already too invested in doing the operation. I think it's ... it would take a really massive thing for you to jar it all … you're already all there. Someone's sharpening the knife, we're... it's going to happen. And if it doesn't happen it's a massive deal to cancel on the day of surgery."* (An-PAC 2)

It is felt to be unfair on the patient to throw this sort of surprise upon them when they are psychologically prepared for an operation.

> *"I don't think it's appropriate, the day of surgery, I think it's very, very unfair for patients to have this kind of conversation on the day of*

> *surgery, they're already anxious, they've already come, psyched themselves up, so to suddenly throw it in the mix and go "Do you think you should have your operation today?", I don't really think so, I, it's, I think super unfair on the patients."* (An-PAC 6)

However, one anaesthetist did tell me of an occasion where she was compelled to have such a discussion on the morning of surgery, even though she felt it was cruel and made her uncomfortable, because the likelihood of things going wrong was so high.

> *"So when I saw her in the morning, I did have quite an explicit chat with her about the fact that I thought she was very high-risk, and that I did ... and I did tell her that she may not wake up from the anaesthetic, but I would do everything I could to get her through, and to get her onto ICU, but she might have a prolonged stay on ICU. And I felt very uncomfortable having that discussion on the morning of surgery, I think that's a pretty cruel thing to do it. But equally, I thought the chances of her deteriorating, were significant enough that I had to."* (An-ICM 3)

7.3.4 Role of the Anaesthetist

7.3.4.1 'I wasn't invited …'

A specific difficulty that anaesthetists face is a lack of clarity over their role when it comes to overall patient management.

> *"I think historically as anaesthetists we've very much been technicians ... there to do a job, there to keep a patient quiet and still while the surgeon performs his operation."* (An-ICM 2)

Unlike physicians or surgeons, anaesthetists are not responsible for the overall care of a patient.

> *"I think anaesthetics is maybe, I don't want to say it's a service specialty, but I do think that patients are admitted and cared for under maybe a surgeon or under a gastroenterologist or under somebody, and we are helping facilitate what's going on."* (An 2)

The organisation of PAC reinforces this. Patients are not referred or scheduled to see a specific anaesthetist, rather they are booked to a nurse-led PAC and then may, or may not, be referred to see whichever anaesthetist happens to be there on that day. Because of this it is uncommon for the anaesthetist in PAC to be the same person who will be anaesthetising the patient.

> *"this is a much more ... one of the things that I feel sad about is that you ... that lots of the patients I sit and talk to in ... almost all of them in Pre-op Assessment Clinic I will not anaesthetise. And I'm very careful when I counsel the patients about what type of anaesthetic they're going to be given, that I won't be giving that anaesthetic because there's ... you know, I have my own ways that I like to do it, my own preferences, my own thoughts about what I think is a good idea and not and that might be very different to the person on the day."* (An-ICM 2)

This can create concern about inserting themselves into the decision-making process.

> *"And so it's ... it's a very jarring experience for me, which is why there has to be quite a high bar, for me entering upon it because I'm going to have to phone a surgeon, or email a surgeon who may potentially be angry about me interfering because I wasn't invited to do so"* (An-ICM 2)

It often requires a major concern or issue to trigger a SDM discussion.

> *"For me it's more of a ... it's not part of my standard pre-assessment ... encounter. It's still much more a biological assessment of whether or not they're going to get through the anaesthetic. How are we going to do the anaesthetic and the immediate post-operative period? It tends to be when I see something that really stands out to me as a terrible idea ... or not going to solve the problem that then I will go the extra effort to start contact[ing] the surgeon, start counselling the patient."* (An-ICM 2)

I was given an example of such a situation where an anaesthetist did feel obliged to intervene.

> *"I think when it doesn't make sense to you yourself. Talking about a specific case of a gynaecological procedure, some major gynaecological laparotomy they wanted us to do on a woman who had a most likely benign ovarian lesion … It wasn't entirely a black or white go/no-go type of decision for them. They were kind of like, oh could do, can do it, but you know on balance perhaps there would be some benefit from taking out this big cyst and deciding what it was. Then you looked at the woman and you thought, well, she's going to die of her other complications way before whatever that cyst is, is going to kill her, and actually if you embark upon this surgical procedure you're almost certainly going to put her on a pathway where she's going to die of the complications of surgery well in advance, so what are you doing? You know? Just did not seem to make sense."* (An-ICM 4)

The lack of a longitudinal relationship between anaesthetist and patient is felt to be a barrier to these discussions. The anaesthetist whom you see in PAC is not *'your'* anaesthetist in the same way that the surgeon whom you see in clinic is *'your'* surgeon.

> *"It was much harder with this lady that I saw on Wednesday, on the grounds that I wasn't her anaesthetist, I was just some interfering person in the process, and I went to see her because obviously none of the surgeons had really spoken to her about her risk."* (An-ICM 3)

Some anaesthetists I interviewed, and observed, were fortunate to have specialist PACs where they assessed *'their own'* patients, i.e. patients whom they would anaesthetise, or a sub-set of patients who either they or a small number of colleagues would anaesthetise e.g. patients who were to undergo a cystectomy or head and neck procedure. This set-up was viewed positively.

> *"I think it's a huge benefit, because I've set up the trust already with that patient, and I've already set up a whole host of things that hopefully when they come back, they'll be able to tell me and in a way what I want them to feel and I suppose this is personal and it's just something that I really want to feel is, is that, we're a team, it's me and them, we're*

> *together in this and as a team, we're going to do this, we're going to get through it and it's going to be great, obviously it might not be so great, but it, it you know, to really give them a sense of continuity, of trust, and of care."* (An 1)

This setup allows the building of a relationship between the anaesthetist and surgeon which makes it easier to ask questions and raise concerns.

> *"So I find other Preassessments very difficult, because I mean I know that I can just literally pick up the phone, speak to my surgeon and say "I'm not entirely sure about this, what are the other options?", and they'll clarify it in an instant, and then I'll be able to actually then have the conversation with the patient in front of me. If I get caught with and I sometimes do in the [General] Preassessment where it's a much bigger hospital, there's many different specialities and the complexity of the surgery and the histology types for all the different types of cancers is actually very, very complex. I don't have the telephone numbers of all those surgeons and I find that if you, if you, especially if you've got a patient in front of you, it may be that you have to send the patient away, to actually then go and track down the surgeon in order to find out their telephone number and then ring them and then sometimes have a follow up conversation with the patient, but I find it very, very difficult."* (An-PAC 6)

7.3.4.2 'It's not really the anaesthetic that is going to be the trouble'

There is a feeling that the *'risk'* lies with the operation as opposed to the anaesthetic and therefore it should be the surgeon who has these discussions.

> *"It's not really the anaesthetic that is going to be the trouble. It's going to be the scale of the procedure so it doesn't feel like you're … I mean you counsel for risks for regional anaesthesia and the specific anaesthetic techniques you're likely to use but the morbidity and the mortality associated with the surgery is not anaesthetic-driven, in my*

> *mind, it's rarely anaesthetic-driven, it's generally surgically-driven so, you know, that's what surgeons should be doing."* (An-ICM 4)

This idea of who *'owns the risk'* was illustrated well during one of my interviews. I was told of a lady in her sixties with metastatic cancer who was presenting for an emergency procedure. Her tumour had caused a blockage in her stomach and she required an endoscopy to try and reopen this. In this case the anaesthetist did proceed to talk to her about her views regarding intensive care and what she would want if her heart were to stop.

> *"So when I spoke to the patient she was very much, she hadn't really had any of those discussions. It was quite a surprise to her actually, and she said oh well I would say yes, I think I should be, you know, if my heart did stop I should have resuscitation and, but I haven't even discussed this with my daughter or my husband, so I need to really speak to them about it."* (An 2)

I asked for what reason he entered into this discussion for this patient when he would not normally do so. He explained that he felt that there was a chance that it would be the anaesthetic management which may be her greatest risk. Because it was anaesthetic risk he felt he needed to have this conversation.

> *"I'm not saying she was going to arrest there and then, but I felt like this is a discussion someone should have had with her. I don't know if I was the appropriate person, but I'm going to be involved in her having a risky procedure, so I felt we should talk about this. I mean maybe there are other patients I should be talking about this to … she also had certainly a complex airway, I just should expand on that, in that securing her airway may have proved problematic perhaps, but the key was she had, because of her obstruction she had a belly full of fluid. And doing a classic rapid sequence on her, or doing an awake technique wasn't really going to be appropriate. So I felt like there's a chance that she may aspirate, and that's, we did talk a little bit about this. So it was more about am I going to increase her morbidity, and*

> *get her to a point where maybe I can't secure her airway, or even if I can there's some damage done to her lungs, and then she has to go to intensive care. These were my, this was my thought process. So that's why I was thinking about it. I think maybe if she didn't have any airway problem, maybe I wouldn't have thought about it so much."* (An 2)

7.3.4.3 'I think as anaesthetists …'

Despite these concerns, I was told of the benefits and skills that anaesthetists can bring. Anaesthetists may be able to bring an element of objectivity because the patient is not *'theirs'*.

> *"I think ironically anaesthetists, even though I'm saying it's not our patient, and they're not under our care, but I think actually we're often a bit more objective, because we're a little bit removed from it. We have experience from being around it, and often we have a bit more clarity."* (An 2)

In some circumstances the absence of an ongoing or long-term relationship may be beneficial.

> *"So the advantage the anaesthetist has is that we can be a little bit more objective in that I do understand for the oncologists and the surgeons they're seeing the patients and the families and they're never going to want to say I can't do anything or we've hit a wall or whatever."* (An-PAC 7)

It is also felt that anaesthetists can bring a broader, more holistic, viewpoint.

> *"the anaesthetist actually brings the holistic view, quite often, to this which is appreciated by the surgeons."* (An-PAC 2)

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> *"I think anaesthetists increasingly are sort of finding that they do have that slightly more objective view point, that maybe some of the more invested clinicians may lack a little of because they are seeing that*

> *patient more through the eyes of like, a scalpel or chemotherapy drugs."* (An-PAC 4)

Partly, this may be because anaesthetics involves a mixture of both medicine and surgical knowledge with a particular focus on a patient's physiology and co-morbidities.

> *"so I think as anaesthetists we are like generalists because we capture various medical and surgical specialties, we treat from new-born babies to elderly patients, pregnant women, critically ill. So we are exposed to a wider width of clinical scenarios and we've got a good understanding of the whole physiology of all the body's system."* (An 3)

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> *"maybe a more holistic view of the patient, more acknowledgment of their comorbidities, their functional status and also the fact that our role is so spread from preoperative to post-operative to intensive care that we, we all are erm, well aware of the consequences of when, outcomes are not good"* (An-PAC 3)

It was felt that this broad, and holistic, assessment may be absent from other specialties.

> *"I think the surgeons they become more and more specialised in their own field, even the Urologists: they do prostates, or they do bladders, or Orthopaedics: they do hand or feet or a knee or elbow or a shoulder. So, they are very, very good at their specialist knowledge in their very narrow field but it is impossible for a human being to also keep the holistic view of the patients"* (An 3)

During my observations I witnessed a good example of this when an anaesthetist was reviewing previous correspondence about a patient prior to them having a minor Head & Neck procedure. A problem list or summary is often included at the top of these medical letters. In this case a letter written by a surgeon outlined four points detailing aspects of previous Head & Neck diagnoses and various operations. A fifth and final point read *'heart transplant'*. This is an example of how each specialty tends to focus solely on their own area of expertise and either does not reflect, or minimally reflects, on other aspects of the patient. Anaesthetists belong to one of the few specialties which must take into consideration all of a patients' diagnoses.

Being a generalist, however, means that anaesthetists often lack the specialist knowledge to counsel patients about alternatives to surgery.

> *"so that's a little weakness when you're just the anaesthetist seeing people in clinic, and particularly more generally, more ... I mean I know more about the operations I do all the time... if I do something for a different team, then I don't know what the other options would be other than this operation on this day. Is there a non-operative way of treating this thing that's acceptable? Is there another operation that's a lower risk type operation."* (An-PAC 2)

In the specialist PACs this is less of an issue because the anaesthetist develops a knowledge base over months and years about alternatives treatments.

> *"So one of my colleagues, she sees this regularly in her clinic, and one of the patients was 'oh I'm not even sure if I want this operation', I'm just very anxious about it. And because she had enough knowledge about the procedure, and about the alternatives, she was able to put this patient in contact with others who could offer alternatives, and she had a discussion with the surgeons."* (An 2)

Working in ICUs is also felt to give anaesthetists an important perspective that others may lack.

> *"I think the difference between anaesthetists with our intensive care background compared to maybe some medical teams that don't have that knowledge of intensive care, and even some surgical … specialties, is that if someone arrests more likely than not they're going to end up in intensive care. So if you think this patient's not appropriate for intensive care for whatever reason, it doesn't mean that you're*

> *necessarily right, but if you feel like that then it gives you some, a different perspective to whether, well hold on then, should we even be doing the resus in the first place? Is it in their interests?"* (An 2)

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> *"working in Critical Care does help me definitely, yeah. Helps me with the phrasing a bit"* (An-ICM 1)

This experience of ICM may result in anaesthetists having greater understanding of the limits and the negative aspects of high-intensity medical treatments.

> *"I think currently most anaesthetists do enough ICM training to be able to see this picture. Whether or not they want to have these conversations ... it may be because I do ICM that I'm more prepared to have these conversations with people. But I don't think there's anything particularly lacking from anaesthetic training that would make you unaware of this problem."* (An-ICM 2)

7.3.4.4 'the person who is best to do this'

It was felt that there was no specialty uniquely best suited to have these discussions. It may be that a combination of people is required.

> *"So whether it means that we should have a group of people who have the discussion, means that you could have somebody who could lead the discussion, who's particularly skilled at it. That you could have the oncologist there, who could talk about what treatment options were available, and you could have the intensivist there who talked about what the treatment options were available on ICU"* (An-ICM 3)

Some form of MDT is felt to be needed.

> *"It's more a joint decision I guess is what I'm thinking. A more of an MDT decision, discussion."* (An-PAC 1)

A challenge of this approach would be how to develop relationships between the patient and multiple practitioners at the same time.

> *"You can make a case, can't you, that it will all be nice if everybody sort of does it together and it's sort of a group thing but these are personal relationships and they're hard to do. That requires coordinating three relationships [anaesthetist, surgeon, intensivist] at the same time. I think it can be done by any of those people. You just really are hoping that the pathway that [the] patient is on at some point has someone who picks up that role and does that properly and each of the various people involved will sometimes be supported by their colleagues who won't be quite as good at that particular contact"* (An-ICM 4)

Perhaps unsurprisingly it was reported that some surgeons perform the role very well and others less so.

> *"I think they get a slightly bad rap actually. I actually think they are incredibly good at understanding their patients. And in fact it's interesting, they've been doing this for years, the counselling bit of patients and doing that and erm, you know I think they are ... they've always been really good at it."* (An-PAC 2)

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> *"there [are] some surgeons that are already very used and very good at doing this pre-filtering so then, I mean most patients that then come to us are probably going to be okay for the operation and there are some other surgeons that heavily rely on the anaesthetic pre-assessment to then make those decisions"* (An 3)

It was felt that they benefit from a longitudinal relationship with the patient.

> *"I think some surgeons are very, very good at it, and in some ways it's easier because they've met the patient several times built up more of a rapport and can understand what they want from surgery."* (An-PAC 3)

This relationship, which extends from the pre-operative into the extended post-operative period, is important when counselling patients.

> *"I think the anaesthetist generally is quite honest about immediate post-operative things that we think the patients would want to know about pain and everything? But I guess in the end it's the long-term results for the patient that are important and it's only the surgeons who actually see them a month afterwards. When they come back and say they've forgotten about how awful it was in hospital and how they're really grateful because now their cancer has been removed"* (An-PAC 1)

GPs were also mentioned as a possibility given their long-term relationship with the patient, but their lack of perioperative knowledge was felt to be a hinderance.

> *"the person who knows the patient, who knows their history. They will have referred them to surgery and I think that is ... that is the person who's best to do this. That said, there's definitely going to be a skills and expertise gap here ... you know, I will add the perioperative anaesthetic bit but there's the surgical bit about having this conversation ... you know, at the same time and those are things that you can't really expect the GP to have."* (An-ICM 2)

7.3.5 Miscellaneous

7.3.5.1 'training' and 'experience'

There was generally an openness towards increased training.

> *"I would be completely open to having more formal training, I think you can always learn ways of you know, communicating, improving your sort of service"* (An-PAC 7)

No participants were able to report specific training around these issues although it was felt this may be more prominent for junior doctors today.

> *“think there’s probably more emphasis now than when I was young and actually having that. There’s a lot more role play and training, simulation training”* (An-PAC 1)

It was felt that these forms of interactive training would be most useful.

> *“I think something that isn’t didactic and isn’t lecture based, I think you know kind of role play, watching, best examples, very interactive approach to these kinds of discussions.”* (An-PAC 4)

Whilst it was felt that training could be useful there was also emphasis placed on the importance of experience.

> *“It’s hard to say. It’s not trainable. But most of it feels like its experience. Medicine’s a bit like that in general, isn’t it? You have to get some of it wrong. You don’t learn as well from others mistakes as from your own.”* (An-ICM 4)

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> *“I mean, I think role play can be very useful, but I think there's nothing quite like actually really doing it, is the bottom line. And of course, people react in such different ways.”* (An-ICM 3)

This experience may be both professional and personal.

> *“I can look back and safely say I was appalling, there’s no two ways about it, and that’s because I was young, inexperienced, but also because I hadn’t been a patient, none of my family members at that point had been a patient, and really you have no concept of what these people are going through, but I suppose you learn and you learn quite horribly by your mistakes in those first few sort of conversations, when you realise that actually that wasn’t handled very well. And you start to be able to read the signs from the people that you’re chatting to and you can see that they’re looking at you, as if to say, where did this come from? What are you talking about? Um, and it, it, it is a learning*

> *curve, but that was experience, so I've learnt by experience, and I've learnt by experience of chatting to people in the hospital, and I've learnt by my own personal life experience, so that's made it slightly easier"* (An 1)

7.3.5.2 'emergencies'

Emergency situations were felt to be distinct with the time pressure meaning decision making is more rushed.

> *"it's sometimes more in the really this operation needs to happen in the next hour or two, we need to make a decision. So this decision-making process is more rushed"* (An 3)

This may bring some advantages as it may make it easier to get people together to have a discussion.

> *"The only difference with the emergency situation is you're more likely to convene an MDT more easily ... so you're more likely to have a surgeon, an anaesthetist, an intensivist, patient, patient's relatives all round a bed space having a sensible conversation then you are in a non-emergency situation when people are sending letters to those who may not necessarily be dealing with that case a few months down the line."* (An-ICM 2)

The decision is usually binary in a way that it may not be in elective cases.

> *"I think it's kind of easier, because the patient doesn't really, or apart from doing anything, they, it's a binary option, you either have the operation, or you don't. I think if they're elective operations, there often are other treatments that radiotherapy or BCG, or chemotherapy or do you have the operation first? Do you have the chemotherapy before or after? So there's a lot more in the mix I think, whereas for an emergency operation actually, you're pretty much stuck. So you're either palliating or not"* (An-PAC 6)

The fact that it is an *'emergency'* acts as a natural frame, or warning shot, for the patient and may make them more open to such a discussion.

> *"Because you've now set the scene, it's an emergency so there is a risk already there, and the word "emergency", "emergency surgery" that for anybody takes it to a different level, you're going into hospital and this is an emergency, that's a completely different ball game, and that is absolutely open, because before you even get to, sort of you know, in the ambulance, if you've come in by ambulance, already those awful thoughts of death have already occurred … everyone is far more open, there's you know, [psychologically], they're sort of you know, willing to have a conversation like that."*(An 1)

Alternatively, the patient may lack capacity or simply not be in a state of mind to have such a discussion.

> *"in an emergency often you're getting a patient who's maybe clinically not even, whether they even have true capacity, whether they're in the right frame of mind, um there's pressure on to do the procedure. So I think there's a big difference between elective and emergency, especially in terms of time"* (An 2)

7.4 Discussion

This is the largest qualitative study assessing HSCPs views of ACP in the perioperative setting and the first conducted in the UK. The headline finding is that ACP, as defined by the GMC (Box 1.1) and NHS Improving Quality (Box 1.2), is generally absent from perioperative practice. The QSE has helped provide a rationale for why this is the case including outlining attitudinal and practical barriers.

Previous research (149) and the KAP-ACP workstream highlighted a concern that the nuances of the perioperative setting necessitate a different approach to issues such as treatment limitations. This was replicated and expanded in the QSE and appears to be the largest reason why ACP is not routine practice. There are three main reasons why treatment limitations, often considered inherent in ACP, are rejected in the perioperative period. Firstly, the general positivity of anaesthetist, and often patient, arises from the relatively low risk of death following surgery. A high-risk patient has been defined as one with a mortality risk of ≥5% (430). This means that those who die following an operation are a small proportion of a small proportion. Discussing ACP and EoL wishes can seem incongruous in these situations. For patients who have an even lower risk of death the advantages of these discussions are thought to be outweighed by the concern that the discussions could cause fear and anxiety. Secondly, the causes of deterioration in the perioperative period are often reversible. Anaesthesia and surgery may precipitate deterioration, e.g. bleeding, allergic reaction, or cardiovascular instability, requiring significant medical intervention. These interventions may well be appropriate in the perioperative setting because the cause is believed to be temporary and reversible whilst the same intervention would be inappropriate in a different context. There is also often a lack of distinction between the normal course anaesthesia and post-operative care, and the high-intensity medical treatments normally referred to in treatment limitations. Finally, there is a belief that the presence of treatment limitations is often indicative that surgery itself is inappropriate. Anaesthesia and surgery often necessitate the use of multiple high-intensity medical treatments. This is the case even if the patient does not suffer any complications. If there is genuine concern that a patient would be unable to recover from such treatments, then it follows that they may be unlikely to recover from surgery. In these situations, the discussion should revolve around whether or not to proceed with surgery. These were termed *'go / no-go'* decisions and require a process of SDM. This may provide an opportunity for a combined model of SDM and ACP.

Decisions about future treatment are an important aspect of ACP and are described in both the GMC and NHS Improving Quality definitions (70,73). They are also legislated for in the MCA in the form of Advance Decisions to Refuse Treatment (90). However, these decisions are not the entirety of ACP. There should also be a focus on wishes, values, and goals which may inform future *'best interest'* decisions should the patient lose capacity (70,73). The QSE found that a focus on an ultimate outcome may actually be more useful for clinicians than decisions about specific treatments. This ultimate outcome may be very similar to the *'transition point'* that was described in the BC workstream. Much of this should be considered during a *'go / no-go'* discussion. With small changes to the way this is conducted and documented it would be possible for this information to advise future decision making should the patient lack capacity. Currently, there is a greater focus on what the patient wants, a best-case scenario in order to determine whether this is realistic. For both SDM and ACP it may be useful to also focus on a minimally acceptable worst-case scenario. If a patient becomes unwell and this minimally acceptable scenario no longer looks achievable it could act as the *'transition point'* at which HSCPs could move from curative to palliative care. This would allow the flexibility required for HSCPs to provide appropriate treatment for often reversible perioperative complications.

Whilst these *'go/no-go'* discussions are more common than ACP discussions they are not routine. It was lamented that the holistic element of PAC, which included SDM, was undervalued and less prominent than that of physical health. The reasons for this appeared to be cultural and logistical as opposed to a lack of knowledge or training or the negative attitudes of participants.

The ethos of PAC is one which revolves around *"getting the patient through the operation"* and avoiding day of surgery cancellations. The ultimate question is normally '*is this patient fit for surgery?'* as opposed to *'what is best for this patient?'*. On two occasions during the observations of the QSE there was no dedicated space in PAC for the anaesthetist. Instead the anaesthetist would *'hop'* from room to room troubleshooting. There are often multiple interruptions during consultations by nursing staff trying to *'close out'* tasks. Without appropriate space, free from interruptions, it is very difficult to have any sort of meaningful conversation. The large time commitment required for these discussions, in competition with multiple other tasks, was observably a challenge. When these discussions did occur, they often led to the clinic overrunning. The organisation of PAC with the anaesthetist seeing nurse referrals also means there is a lack of predictability of workflow. On some occasions there may be no high-risk patients who need to be reviewed and on others there may be four or five. Another organisational aspect of PAC which inhibits SDM is the timing of the consultation. Frequently patients attend only one or two weeks prior to their operation. At this point they will have been given a date for surgery, expectations have been set, and plans have been made. Introducing a *'go / no-go'* discussion at this point can be fraught with concerns about upsetting both the patient and/or the surgical team. One aspect of PAC which supports SDM is the use of a triage system. Low-risk patients are seen in a nurse-led PAC and it is only high-risk patients who will have a *'face-to-face'* with an anaesthetist. It is these high-risk patients who are both most likely to be referred for a *'face-to-face'* and who would most benefit from a SDM discussion.

The attitudes of participants towards their own specialty of anaesthesia is interesting. There is a belief that anaesthetists are able to bring certain skills to these discussions: objectivity; a broader, more holistic viewpoint; and an experience and understanding of high-intensity treatments. However, it is not clear what the role of an anaesthetist, or PAC, is in terms of decision making as anaesthetists are not responsible for the overall care of the patient. Frequently, there is often no relationship between anaesthetist and surgeon. The structure of PAC means that patients are listed for surgery, scheduled to attend PAC, and then referred to see an anaesthetist by a PAC nurse. The lack of a direct referral from a surgeon, or other primary clinician, to see an anaesthetist can result in a concern that they have not been *"invited"* to this discussion. Similarly, in most cases the anaesthetist the patient sees in PAC will not be the anaesthetist who will anaesthetise them on the day of surgery. This one interaction may well be the sum of their entire relationship and so embarking on a challenging and unexpected conversation in such circumstances is difficult. Finally, there may be reluctance to open this conversation because of a lack of knowledge about alternative treatment options. Raising the spectre of not proceeding with surgery is difficult when one feels unable to outline what the non-surgical treatment will look like. Specialty PACs help to solve many of these concerns. Here, anaesthetists are able to develop a longitudinal relationship with their patients; rapport with the surgeons; and an understanding about the intricacies of particular surgery and of alternative options.

None of these issues: space, time, timing, or the lack of relationship between anaesthetist and patient or surgeon, are absolute blocks to *'go / no-go'* discussions. It is rather, that these all raise the bar to entering such a discussion a little higher. One participant described only opening these discussions *"when I see something that really stands out to me as a terrible idea"*. It is likely that there are patients who would benefit from these discussions even if the surgery does not meet the high bar of being *"a terrible idea"*.

7.4.1 Limitations

The QSE has several limitations that are common to all qualitative studies. I have documented the attitudes, opinions, and experiences of anaesthetists use of perioperative ACP in a single central London teaching hospital. It may not be possible to infer these findings to anaesthetists, and other HSCPs, in different institutions, settings, or countries. The use of national surveys in a mixed methods approach alongside the QSE is an attempt to address this. It is possible that my own preconceptions may have influenced, or biased, the conclusions of this study. I have attempted to account for this by systemically acknowledging, assessing, and sharing these through the process of reflexivity (198). The choice of thematic analysis also has limitations. A commonly quoted disadvantage of using a thematic approach to analysing qualitative data is that one can lose a sense of continuity and contradiction through an individual account (299). I attempted to account for this by including additional surrounding text when coding. Despite this, the nature of collating multiple individual accounts in order to summarise and form conclusions inevitably results in the diminishing of the individual account.

7.5 Conclusion

The QSE has described a lack of perioperative ACP and provided a rationale for its absence. There are three main reasons why the treatment limitations, often considered inherent in ACP, are rejected in the perioperative period: the general positivity created by the low risk of death; the often reversible nature of surgical complications; and that the presence of treatment limitations is often indicative that surgery itself is inappropriate. For this to change a new model incorporating ACP into SDM discussions would be most appropriate. Currently SDM discussions are also hampered by multiple practical and attitudinal barriers. The two most important are the cultural focus of PAC on physical health and the lack of clarity over the role of the anaesthetist in the patient journey towards surgery.

8 Discussion

The aim of this thesis was to describe the important components of EoL and ACP discussions and highlight barriers which may prevent such conversations in the perioperative period. This has been achieved by conducting two systematic reviews, two national surveys of UK anaesthetists, and a qualitative workstream involving interviews and observations in a single London centre. As discussed in Section 2.2.4.3 the integration of different workstreams is a crucial design feature of mixed methods research. Throughout this thesis the findings of workstreams have been incorporated into the design of subsequent workstreams. The goal of this final chapter is to interpret and integrate the findings of all five workstreams into an explanatory narrative.

The first research question sought to describe anaesthetists' knowledge, training, and understanding of ACP. The SR-KAP found that questions focussing on specific legislation tended to be answered incorrectly by HSCPs. It also found nurses scored higher on general questions about ACP (345–350) whilst nursing home managers and home care package case managers scored poorly and lacked confidence in their levels of knowledge (351,353). The SR-pACP found that physicians tended to rate themselves highly in terms of their knowledge and preparedness to engage with ACP (227,229,230). Similarly, the KAP-ACP demonstrated anaesthetists had a high level of knowledge when asked questions about ACP based on guidance from the GMC (70); Royal College of Physicians (113); NHS Improving Quality (73); and the Mental Capacity Act (2005) Code of Practice (94). The KAP-ACP found that around one third of respondents believed they had sufficient knowledge and training to discuss ACP with patients, around one third did not, and one third were unsure. Participants in the QSE were open to further training and felt that it could be of benefit, particularly for more junior anaesthetists. However, a lack of training did not emerge as a key reason for the absence of ACP or SDM. Participants in the QSE tended to view experience as an equal, if not more important, prerequisite for having these discussions. Studies included in the SR-pACP in which training was mentioned found there was concern over the type and quality on offer. A lack of observation and feedback was frequently described as well as an absence of formal training. The importance of feedback and the role of simulated patients were described as early as the 1970's (431) and recently, there has been a proliferation of EoL care communication skills training interventions (432). These include role-play, group work, and reflection and discussion as well as more traditional lectures and presentations (432). Participants in the QSE agreed that interactive models such as role-play and simulation were likely to be the most appropriate when teaching components of ACP. Whilst knowledge and training did not emerge as major barriers to perioperative ACP in this study these results must be caveated. The studies included in the SR-pACP and SR-KAP, and the KAP-ACP are all at risk of non-response bias. They may well overestimate the knowledge of HSCPs as only those who have an interest in ACP, and are therefore likely to be more knowledgeable, may choose to complete the surveys. Similarly, the QSE was conducted in a London teaching hospital with strong institutional support for the idea of perioperative medicine. This may have resulted in participants having greater knowledge and experience of these issues than those in other hospitals around the country. It is generally accepted that education and training have a beneficial impact on the knowledge and attitudes of those who take part (433). Despite this, a systematic review of postgraduate training programmes found that whilst most were associated with improved knowledge and confidence there was much less certainty about their impact on clinical or patient outcomes (433). There will be a role for education and training, particularly involving role-play and simulation, to promote and support perioperative ACP amongst HSCPs. However, the findings of this study suggest that such a programme would not result in significant change if implemented alone.

The second research question aimed to outline the attitudes of anaesthetists towards their own EoL care. This was the only research question that was primarily answered by a single workstream. The BC workstream found that broadly anaesthetists wished to be well informed; to avoid high-intensity medical treatments if terminally unwell; to spend remaining time with family and friends; and to be symptom free and well cared for. However, there were some respondents who reported different, and indeed contrary, opinions. This highlights the importance of personalising EoL care and engaging in early discussion so that care reflects an individuals’ values, wishes, and preferences.

The foundation of the *'bigconversations'* questionnaire was the work of *'The Conversation Project'* and this was supported by an extensive content validity process involving national experts in a variety of disciplines related to EoL care. The quantitative questions of the *'bigconversations'* questionnaire had low numbers of missing answers and the major themes of these questions were replicated in the qualitative component. This suggests that these themes of *'patient engagement'*; *'intensity of treatment'*; and the *'role of family and friends'*, are indeed critical elements of ACP and EoL discussions. These have also been described as important components of a *'good death'* in previous research (238,239). The qualitative analysis allowed the identification of new themes: the idea of a *'transition point'*; *'care'*; and the desire to make plans for *'after death'*. Having identified these six themes the question becomes which of these could be incorporated into a perioperative ACP discussion.

The QSE found that discussions around death can seem incongruous given the general positivity surrounding surgery which is created by the low risk of mortality. This was also reflected in the KAP-ACP where respondents indicated that a form of triaging was necessary to determine which patients should have an ACP discussion. The KAP-ACP did not find widespread support for the idea that pre-operative ACP would induce fear or unease in patients, but this was a concern of some respondents and this finding was repeated in the QSE. In particular, there was a feeling that if the risk of death is very small then to introduce the idea may be counterproductive. For this reason, discussing specific plans for *'after death'* or indeed *'care'* at EoL are unlikely to be widely adopted. In small number of extremely high-risk cases there may be utility in discussing these issues, but this will not be the case for the vast majority of those undergoing elective surgery. The absence of perioperative ACP described in the QSE was found to be the result of a view that treatment limitations are inappropriate in a surgical population. This is because of the general positivity created by the low risk of death; the often-reversible nature of surgical complications; and that the presence of treatment limitations is often indicative that surgery itself is inappropriate. This limits the applicability of discussions about *'intensity of treatment'*. However, the idea of a *'transition point'* may provide a partial solution. A focus on an ultimate outcome, in this case a minimally acceptable quality of life, would allow greater flexibility for the perioperative team should a patient suffer complications. It allows for different decisions to be taken depending on events and circumstances: some of which may never have been contemplated by the patient or HSCPs. The judgement of HSCPs about the reversibility of complications and the likelihood of survival with the desired quality of life can then be utilised. This allows HSCPs to accept the burden of decision making, which should be there preserve given their knowledge and experience, but to do so with a clear goal that has been set by the patient. There may also be a subtle difference between asking patients about what treatments they wish to reject as opposed to what quality of life they would find acceptable. The former may be considered as inherently negative and assuming of a bad outcome. In contrast, the latter could be framed with survival as the goal and expectation. This would only be relinquished in a small number of circumstances as dictated by the patient. The *'role of family and friends'* was also highlighted in the QSE as providing helpful information when contained in an AD. Additionally, the QSE described the challenge of communicating risk to patients and how there is both a spectrum of understanding and also a spectrum of *'patient engagement'*. Deciphering this is an important part of any SDM discussion. Some patients may wish to *"bury their head"* whilst others want to be informed of all possibilities and be intimately involved in decision making. This information, about a *'transition point'*, the *'role of family and friends'*, and the level of *'patient engagement'* would be of use to clinicians at a later date to better inform treatment decisions and discussions should a patient become critically unwell.

The third research question sought to describe the attitudes of anaesthetists towards ACP. The KAP-ACP workstream found broad support and a positive attitude towards ACP amongst UK anaesthetists. The SR-KAP and SR-pACP found similarly positive attitudes of HSCPs towards both ACP and perioperative ACP respectively. The run-up to major surgery was seen as an appropriate time for ACP by respondents of the KAP-ACP and in studies included in the SR-pACP. There was overwhelming agreement amongst respondents of the KAP-ACP with the fundamental principal behind ACP, autonomy, demonstrated by the support for following a patient's wishes even if they disagreed with the decision. This is perhaps unsurprising given the prominence given to autonomy by anaesthetists when discussing wishes for their own EoL care in the BC workstream. This support for the principle of autonomy was replicated amongst other HSCPs in the SR-KAP, however, worryingly the SR-KAP also found evidence of HSCPs providing, or witnessing others provide, treatment prohibited by a patient's AD. The SR-pACP described how some HSCPs were concerned that the inherent ambiguity of ADs limited their utility in clinical situations. This was not widely supported by findings from the KAP-ACP workstream, however, this idea was described in the QSE. Unlike the SR-pACP, where there was no mention of anaesthesia as the appropriate specialty to have perioperative ACP discussions, the KAP-ACP found respondents supported the idea that ACP was a responsibility of anaesthetists. The QSE explored this in greater detail and found that participants believed anaesthetists have much to bring to ACP and SDM discussions. This includes an objectivity; a broader, more holistic viewpoint; and an experience and understanding of high-intensity treatments. However, there was a lack of clarity over their role in the patient pathway which limits their involvement. There is a concern that the anaesthetist has not been *"invited"* to the decision-making process and this can result in a hesitance to become involved. Additionally, the lack of a long-term or longitudinal relationship with the patient was highlighted as a potential barrier in both the QSE and KAP-ACP.

The data collected using survey instruments, including the KAP-ACP and studies included in the SR-pACP and SR-KAP, demonstrates a widespread support for ACP both generally and in the perioperative period. This would suggest that the negative attitude of anaesthetists or HSCPs are unlikely to be a major barrier to ACP. However, the widespread support for ACP amongst healthcare leaders means this research may suffer from a degree of *'courtesy bias'*, where respondents provide the answers which they feel they *'should give'* (333). The qualitative comments of the KAP-ACP and the findings of the QSE both imply more nuanced opinions of perioperative ACP. They suggest a rejection of treatment limitations in the perioperative setting and concerns over whether ACP or *'go / no-go'* discussions are the remit of anaesthetists. Both of these beliefs represent barriers to anaesthetists engaging in perioperative ACP.

The final research question sought to outline current practice of ACP by anaesthetists in the perioperative setting. The KAP-ACP found the majority of respondents reported that they had at least one ACP discussion every 6 months. However, 20% reported never having had such a discussion and 49% of respondents stated that they do not routinely have ACP discussions in the run-up to major surgery. During the observations for the QSE there were no examples of an ACP discussion involving EoL wishes or treatment preferences. When questioned participants agreed that these discussions were very uncommon. This did not mean that that there were no discussions about patient values, wishes, and preferences. These conversations do occur, but they revolve around the *'go / no-go'* decision for surgery. These act as a proxy for the treatment limitation component of ACP with a decision to proceed bringing with it an expectation that the patient should receive maximum treatment.

The *'go / no-go'* discussions are not themselves routine. Partly, this is a result of triaging, whereby only high-risk patients are seen by an anaesthetist with others attending a nurse-led PAC. The general consensus from the KAP-ACP and QSE was that this form of triaging is the correct approach as discussions could, and should, not happen with every patient. For those who are at low risk of complications it was felt that the risk of causing anxiety and fear would outweigh any benefit. However, even for patients who may be high-risk there are a variety of factors which may prevent these discussions. A lack of physical space, frequent interruptions, and a lack of a managed workflow all arose from the QSE as barrier to anaesthetists having long and challenging conversations. The time required for these discussions was described as a minimum of 30 minutes. Despite this half of respondents to the KAP-ACP denied that ACP discussions would take too much time and participants in the QSE believed that they would make the time if they felt it was necessary. This is in contrast to the SR-KAP where HSCPs felt that a lack of time was a major barrier to engaging in ACP. The timing of the consultation was highlighted as a key barrier in both the KAP-ACP and QSE. There was a rejection of having these discussions on the morning of surgery as it would be unfair to throw such a surprise to patients when they are prepared for surgery and it would not allow the required time for reflection. Even PAC appointments are often felt to be too close to the date of surgery to be able to open such discussions. These issues of physical space; interruptions; time; and timing do not prevent ACP or SDM, but they do result in a higher threshold to trigger these discussions.

8.1 Recommendations

To incorporate ACP into perioperative care requires a redesign of ACP specifically for the surgical setting. Current advice surrounding Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders at the time of surgery explains that in almost all cases they require either suspension or modification to allow surgery to proceed (434) and this highlights the necessity for more bespoke ACP for the perioperative period. It is unlikely that a focus on traditional ACP with its connotations of treatment limitations and EoL care will be successful. Instead, these discussions should be nestled within already occurring *'go / no-go'* discussions. Issues such as the level of *'patient engagement'* desired and the *'role of family and friends'* are already prevalent in these discussions. Clearer documentation of these would provide useful information for HSCPs when making *'best interest'* decisions if the patient goes on to lose capacity. In addition to this a focus on a minimally acceptable quality of life as an ultimate outcome would allow for the flexibility required by the perioperative team.

To encourage greater numbers of these mixed SDM / ACP discussions a redesign of PAC is required. A division of PAC into *'pre-assessment'* and *'high-risk'* clinics would be the first step. A specific *'high-risk'* clinic where an anaesthetist is tasked only with *'face-to-face'* consultations with *'high-risk'* patients would remove many of the practical barriers identified. The *'high-risk'* clinic would require appropriate physical space and would schedule patient appointments allowing for a suitable amount of time to have in-depth discussions. This time period would need to be a minimum of 30 minutes but ideally may allow for 45-60-minute appointments. It would shield the anaesthetist in the *'high-risk'* clinic from the multiple other tasks and queries which can often interrupt and crowd out SDM. Patients attending such a clinic could be pre-warned that the focus of this consultation would be a SDM process about whether or not to proceed with surgery. To implement this would necessitate a triage system. The Royal College of Surgeons of England and the Department of Health have previously defined the a high-risk patient as one with a predicted hospital mortality ≥5% (430). This figure could be used as an initial trigger for referral to a *'high-risk'* clinic although this would depend on local or institutional factors. This referral should be made at the time of the surgical appointment where surgery is first *'contemplated'* (23). Ideally, the referral should be made by the surgical team to counteract the idea that the anaesthetist is *"not invited"* and would be interfering in the process. This would also allow the surgical team to provide information about alternative options or specific information which might make surgery preferable or challenging. In addition to referral, the appointment at the *'high-risk'* clinic must take place earlier than is currently the case to allow it to feed into the decision-making process. For conditions where an operation is only one of multiple treatments this would allow for the *'high-risk'* clinic to feed into the MDT meeting and decision making. For operations which are often, or always, *'high-risk'* a *'specialty-specific PAC'* may be the most appropriate model. The use of *'specialty-specific PACs'* was viewed positively by participants in the QSE. These allow the development of a relationship between anaesthetist and surgeon and for the anaesthetist to gain knowledge of the likely course and complications of the operation and possible alternatives. They often already incorporate many of the features of the *'high-risk'* clinic described above and if possible, there use should be increased.

8.2 Limitations

This study should be interpreted with its limitations in mind. The specific limitations of each methodology have been separately detailed in each chapter. The goal of mixing quantitative and qualitative methods was to minimise these limitations by complementing them with findings from other workstreams. This has allowed both a broad exposition of practice and views across the population of UK anaesthetists but also a deep exploration of the nuances and subtleties of these beliefs. It is likely that the findings of the QSE are broadly transferable to other similar settings around the country, but it is not possible to know for sure. Similarly, it is likely that the SR-pACP, SR-KAP, BC, and KAP-ACP provide a broad representation of the knowledge, attitudes, and practice of HSCPs and anaesthetists. However, issues of publication bias, non-response error, and courtesy bias may all impact the validity of the findings.

The largest limitation of this study is that it focusses solely on anaesthetists. The SR-pACP and SR-KAP highlight some of the views of other HSCPs but the views and attitudes of patients are not addressed. This was a pragmatic decision to limit the scope of the study to make it manageable and practicable to be completed by a single researcher. However, the goal of all clinical research is to improve patient outcomes and so future research should focus on their views and the reality of their journey through the surgical pathway. For all ACP, not just perioperative ACP, it remains unclear whether patients value it as much as healthcare leaders. The low AD completion rates in the UK support the hypothesis that they may not. The views of patients, in addition to the views and practices of other HSCPs, should be addressed in future research.

Overall, this thesis *'sets the scene'* and allows for greater understanding of current practice and the reasons for this. From this, recommendations have been derived but there has been no *'intervention'* which proves that this impacts care or improves patient outcomes. These recommendations are based on the research outlined in this thesis but whether these are possible, or whether they would be beneficial has not been explored. Future research should address the implementation of these recommendations and the impact they have on patient care and outcomes.

Despite these limitations this thesis demonstrates a robust mixed methods approach to exploring a complex and nuanced topic. Two systematic reviews have synthesised the literature surrounding perioperative ACP and the use of KAPs to investigate ACP. The thesis also includes two national surveys of UK anaesthetists including the first exploring UK physicians own EoL preferences. Finally, this thesis includes the largest qualitative study investigating HSCPs views of ACP and the first conducted in the UK.

9 Conclusion

This thesis has demonstrated that perioperative ACP is not a routine part of UK anaesthetists' practice for patients approaching surgery. There are three main reasons why the focus on treatment limitations and EoL care, often considered inherent in ACP, are rejected in the perioperative period: the general positivity created by the low risk of death; the often reversible nature of surgical complications; and that the presence of treatment limitations is often indicative that surgery itself is inappropriate. For perioperative ACP to be adopted it will require a redesign of ACP specifically for the surgical setting.

Pre-existing discussions about whether to *'go / no go'* with surgery could be modified to provide useful information for HSCPs should the patient suffer complications and lose capacity. Of the six themes that were identified when considering the critical elements of ACP or EoL discussions: *'patient engagement'*; *'intensity of treatment'*; the '*role of family and friends'*; the idea of a *'transition point'*; *'care'*; and the desire to make plans for *'after death'*, three could successfully be included in a perioperative ACP discussion. Information about the level of *'patient engagement'* desired and the role of *'family and friends'* will often emerge from these discussions and would require appropriate documentation. In addition, discussion surrounding a patient's minimally acceptable quality of life would provide useful information if HSCPs are required to make *'best interest'* decisions at a later point. This emphasis on an ultimate outcome would allow for the flexibility required by clinicians in the perioperative period.

There are two major barriers which prevent anaesthetists engaging in these discussions: the cultural focus of PACs on physical health and a lack of clarity over the role of the anaesthetist in the patient's journey towards surgery. The focus on physical health results in the organisation of PAC in a way which does not provide sufficient space and uninterrupted time for in-depth discussions with patients. The timing of these clinics is often too close to surgery, limiting the ability to have these discussions and then feed into the decision-making process. The structure of PAC also results in a lack of any longitudinal relationship between anaesthetist and patient or surgeon and can result in anaesthetists feeling they have not been *“invited”* to the decision-making conversation.

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11 Appendices

Appendix 1 Sample Search Strategy SR-pACP

(Advance Care Planning" [Mesh] OR "advanced care planning" OR "advance care discussion" OR "shared decision making" OR “end of life” OR “goals of care”)

AND

(curriculum OR training OR teaching OR certification OR graduate OR schools OR education OR “internship” OR “residency” OR attitudes OR knowledge)

AND

(perioperative OR preoperative OR surgery OR operation OR anaesthetist OR anesthesiologist OR surgeon)

Appendix 2 Data Extraction Form SR-pACP

Field	**Response**
Country where the study took place	Free text
Type of article	Survey on knowledge of healthcare professionals
	Survey on attitudes of healthcare professionals
	Editorial or commentary
	Description of training program without evaluation
	Description of training program and evaluation
	Other
Study Design	Quantitative
	Qualitative
	Mixed methods
Professional group	Anaesthetists
	Surgeons
	Both
	Other
What is the level of knowledge reported by healthcare professionals (HCPs) involved in perioperative care with regards to having end of life (EoL) and advance care planning (ACP) conversations in the perioperative setting?	Free text
Are there any specific knowledge gaps identified which prevent or hinder HCPs from having EoL / ACP conversations in the perioperative setting?	Free text
Are there any training limitations identified that prevent or hinder HCPs from having EoL / ACP conversations in the perioperative setting?	Free text
What are the attitudes of HCPs towards having EoL / ACP conversations in the perioperative setting?	Free text
How confident do HCPs report feeling in having EoL / ACP conversations in the perioperative setting?	Free text
Educational interventions described.	Free text
Are there any recommendations for the development of educational interventions?	Free text
Additional comments	Free text

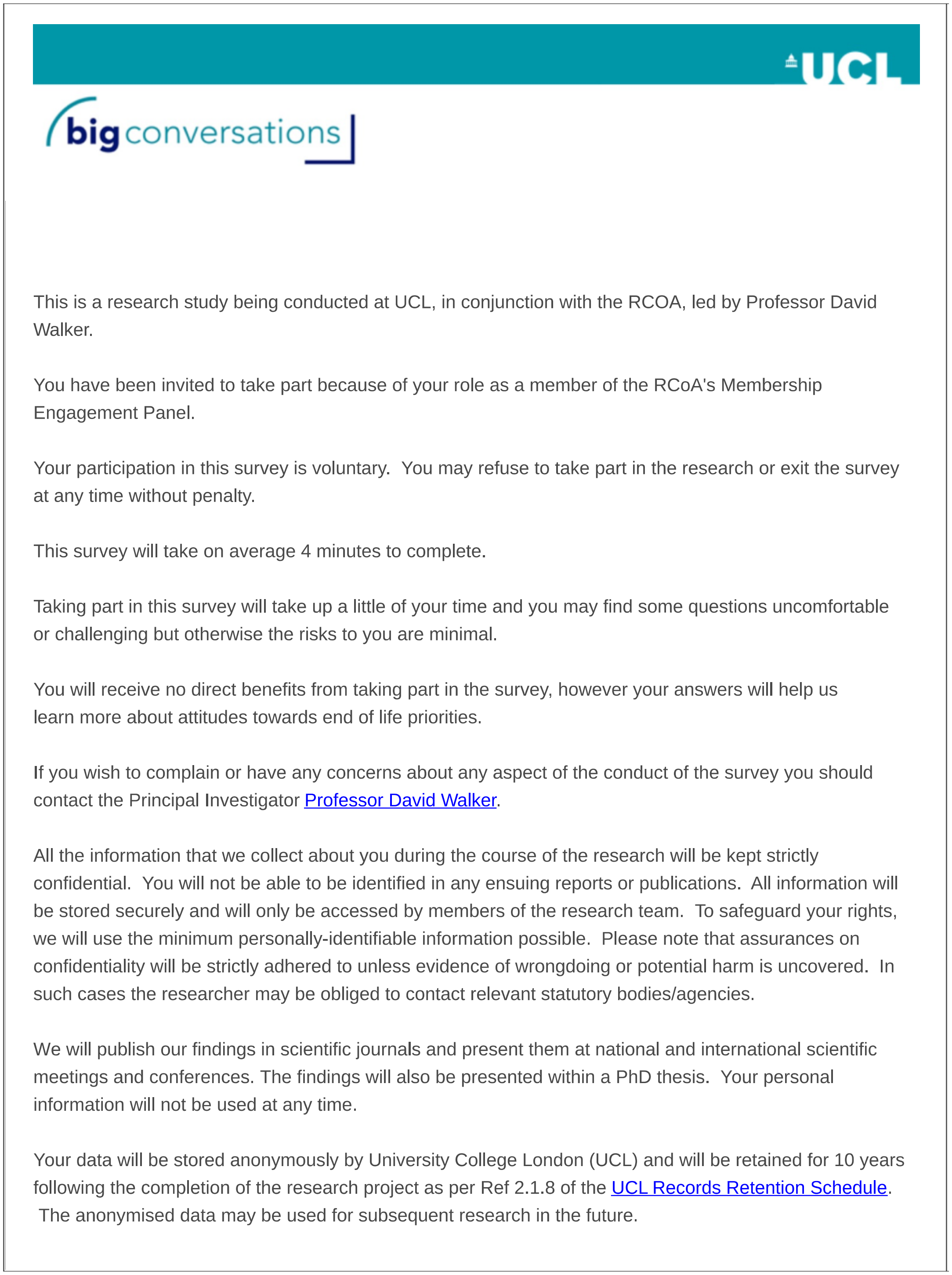
Appendix 3 Survey Quality Assessment Tool

Title & Abstract	Is the design of the study stated in the title or abstract?
Introduction	Is the purpose or the aim of the research clearly explained?
	Is the research question or hypothesis clearly stated?
	Why was the research necessary and has it been placed in the context of previous relevant work?
	Is the study design appropriate to the research question? In particular why is a survey / questionnaire the best method?
Methods	
Questionnaire Development & Formatting	Is the research instrument adequately described?
	Were there any existing measures (questionnaires) that the researchers could have used? If so, why was a new one developed and was this justified?
	Were the psychometric properties of a previously developed measure (questionnaire) presented?
	Were references to a previously developed measure (questionnaire) presented
	Did researchers report how item generation occurred?
	During development of the questionnaire were important domains (categories or themes) used to guide item generation?
	During development of the questionnaire were techniques such as semi-structured or in-depth interviews or focus groups used to guide item generation?
	During development of the questionnaire was an assessment of clinical sensibility performed?
	During development of the questionnaire was an assessment of clarity performed?
	Did researchers report how item reduction occurred?
	What format did the questions take e.g. open versus closed?
	Was the questionnaire pre-tested?
	What was the number of questionnaire items per page? The number of items is an important factor for the completion rate.
	Over how many pages was the questionnaire distributed? The number of items is an important factor for the completion rate.
Validity	What clams for validity have been made and are they justified?
Reliability	What clams for reliability have been made and are they justified?
Piloting	Was the questionnaire pilot tested?
	How was the piloting exercise undertaken—what details are given?
	Was the questionnaire adequately piloted in terms of the method and means of administration, on people who were representative of the study population?
	In what ways was the definitive instrument changed as a result of piloting?
Sampling	Was the target population defined?
	Was the sample representative of the target population?
	How many and what type of attempts were made to contact subjects?
	Is there a description of who approached potential participants (e.g., identification of who signed the covering letter)?

	Is there a description of the survey population and the sample frame used to identify this population?
	Do the authors provide a description of how representative the sample is of the underlying population?
	Is a sample size calculation or rationale/justification for the sample size presented?
	Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for the non- representative sample; if so, please describe the methods.
Distribution & Administration	How was the questionnaire distributed / administered?
	How were potential subjects identified?
	How many and what type of attempts were made to contact subjects?
	Who approached potential subjects?
	Where were potential subjects approached?
	Do the authors report whether incentives were provided (financial or other)?
Response Rate	Was the response rate reported?
	Is the method for calculating response rate provided?
	Were strategies used to enhance the response rate (including sending of reminders)?
	Have any potential response biases been discussed?
	Was the response rate sufficient to enable generalizing the results to the target population?
	Was the amount of missing data reported?
Coding & Analysis	What sort of analysis was carried out and was this appropriate? (e.g. correct statistical tests for quantitative answers, qualitative analysis for open ended questions)
	What measures were in place to maintain the accuracy of the data, and were these adequate?
	Is there any evidence of data dredging—that is, analyses that were not hypothesis driven?
	What methods of dealing with incomplete surveys were used?
Results	Were the results clearly and transparently reported?
	Do the results answer the research question?
	Are quantitative results definitive (significant), and are relevant non-significant results also reported?
	Have qualitative results been adequately interpreted (e.g. using an explicit theoretical framework), and have any quotes been properly justified and contextualised?
	Were the results succinctly summarized?
Discussion & Conclusions	Were the implications of the results stated?
	Are other interpretations considered and refuted?
	Are the results summarized with reference to the study objectives?
	Are the strengths of the study stated?
	Are the limitations of the study (taking into account potential sources of bias or imprecision) stated?
	Is there explicit discussion of the generalisability (external validity) of the results?

	Have the findings been placed within the wider body of knowledge in the field (e.g. via a comprehensive literature review), and are any recommendations justified?
Additional	Was the questionnaire provided in its entirety?
	Has study funding been reported?
	Was the survey approved by a suitable ethics panel?
	Was a procedure for informed consent explained?

Appendix 4 bigconversations Questionnaire



This is a research study being conducted at UCL, in conjunction with the RCOA, led by Professor David Walker.

You have been invited to take part because of your role as a member of the RCoA's Membership Engagement Panel.

Your participation in this survey is voluntary. You may refuse to take part in the research or exit the survey at any time without penalty.

This survey will take on average 4 minutes to complete.

Taking part in this survey will take up a little of your time and you may find some questions uncomfortable or challenging but otherwise the risks to you are minimal.

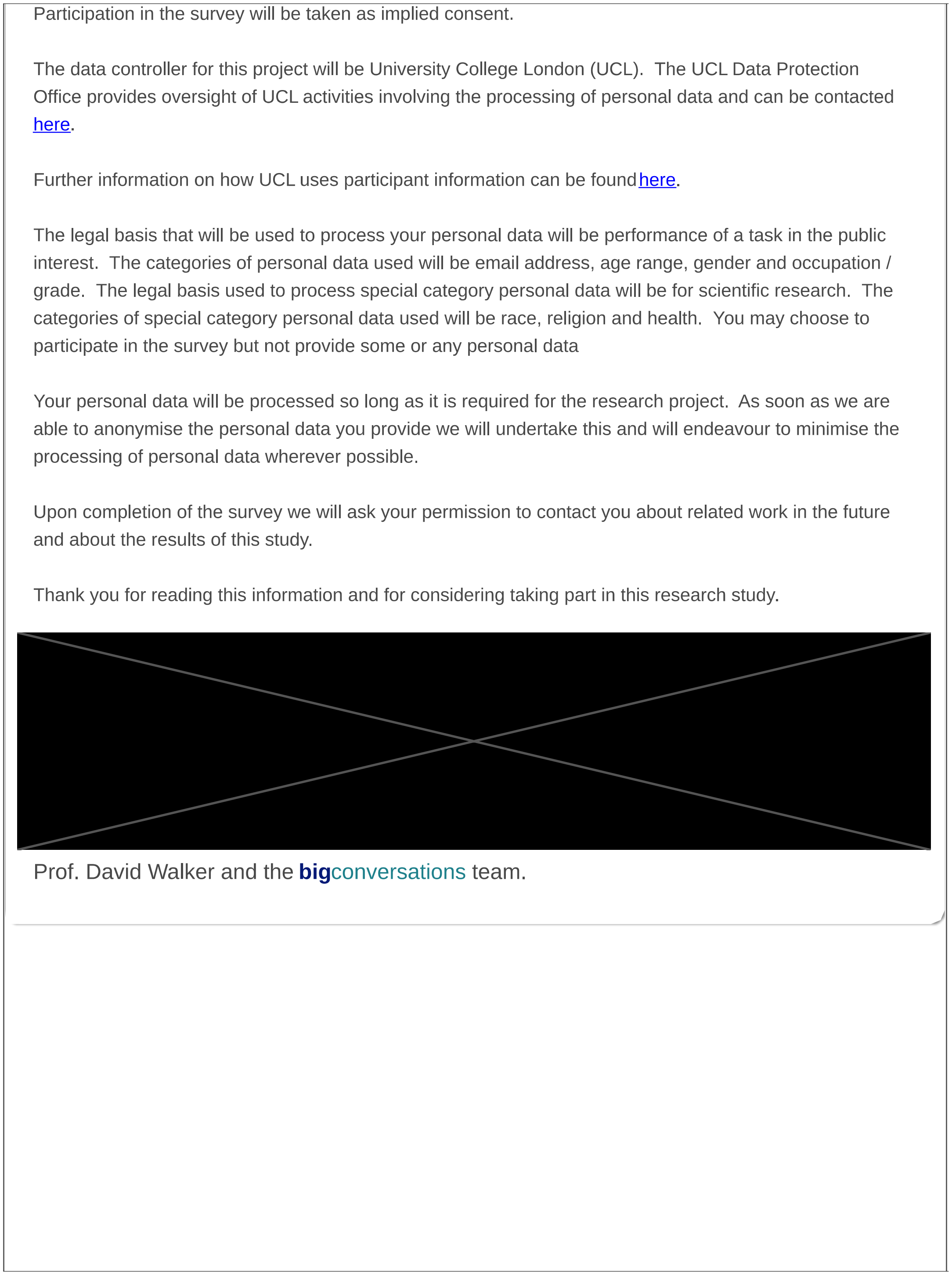
You will receive no direct benefits from taking part in the survey, however your answers will help us learn more about attitudes towards end of life priorities.

If you wish to complain or have any concerns about any aspect of the conduct of the survey you should contact the Principal Investigator Professor David Walker.

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. All information will be stored securely and will only be accessed by members of the research team. To safeguard your rights, we will use the minimum personally-identifiable information possible. Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the researcher may be obliged to contact relevant statutory bodies/agencies.

We will publish our findings in scientific journals and present them at national and international scientific meetings and conferences. The findings will also be presented within a PhD thesis. Your personal information will not be used at any time.

Your data will be stored anonymously by University College London (UCL) and will be retained for 10 years following the completion of the research project as per Ref 2.1.8 of the UCL Records Retention Schedule. The anonymised data may be used for subsequent research in the future.



Participation in the survey will be taken as implied consent.

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data and can be contacted here.

Further information on how UCL uses participant information can be found here.

The legal basis that will be used to process your personal data will be performance of a task in the public interest. The categories of personal data used will be email address, age range, gender and occupation / grade. The legal basis used to process special category personal data will be for scientific research. The categories of special category personal data used will be race, religion and health. You may choose to participate in the survey but not provide some or any personal data

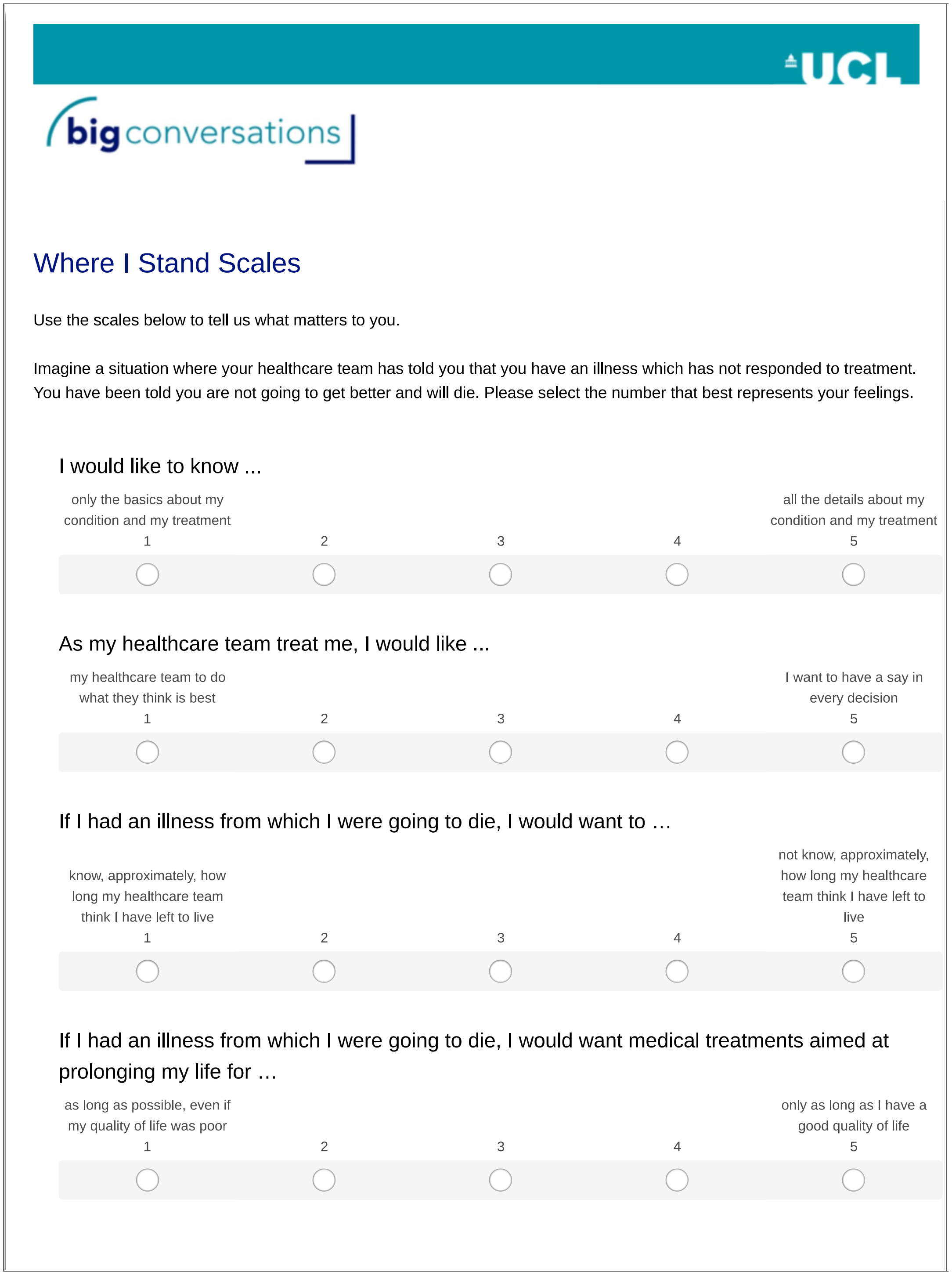
Your personal data will be processed so long as it is required for the research project. As soon as we are able to anonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

Upon completion of the survey we will ask your permission to contact you about related work in the future and about the results of this study.

Thank you for reading this information and for considering taking part in this research study.

[redacted]

Prof. David Walker and the **big**conversations team.



Where I Stand Scales

Use the scales below to tell us what matters to you.

Imagine a situation where your healthcare team has told you that you have an illness which has not responded to treatment. You have been told you are not going to get better and will die. Please select the number that best represents your feelings.

I would like to know ...

only the basics about my condition and my treatment				all the details about my condition and my treatment
1	2	3	4	5
○	○	○	○	○

As my healthcare team treat me, I would like ...

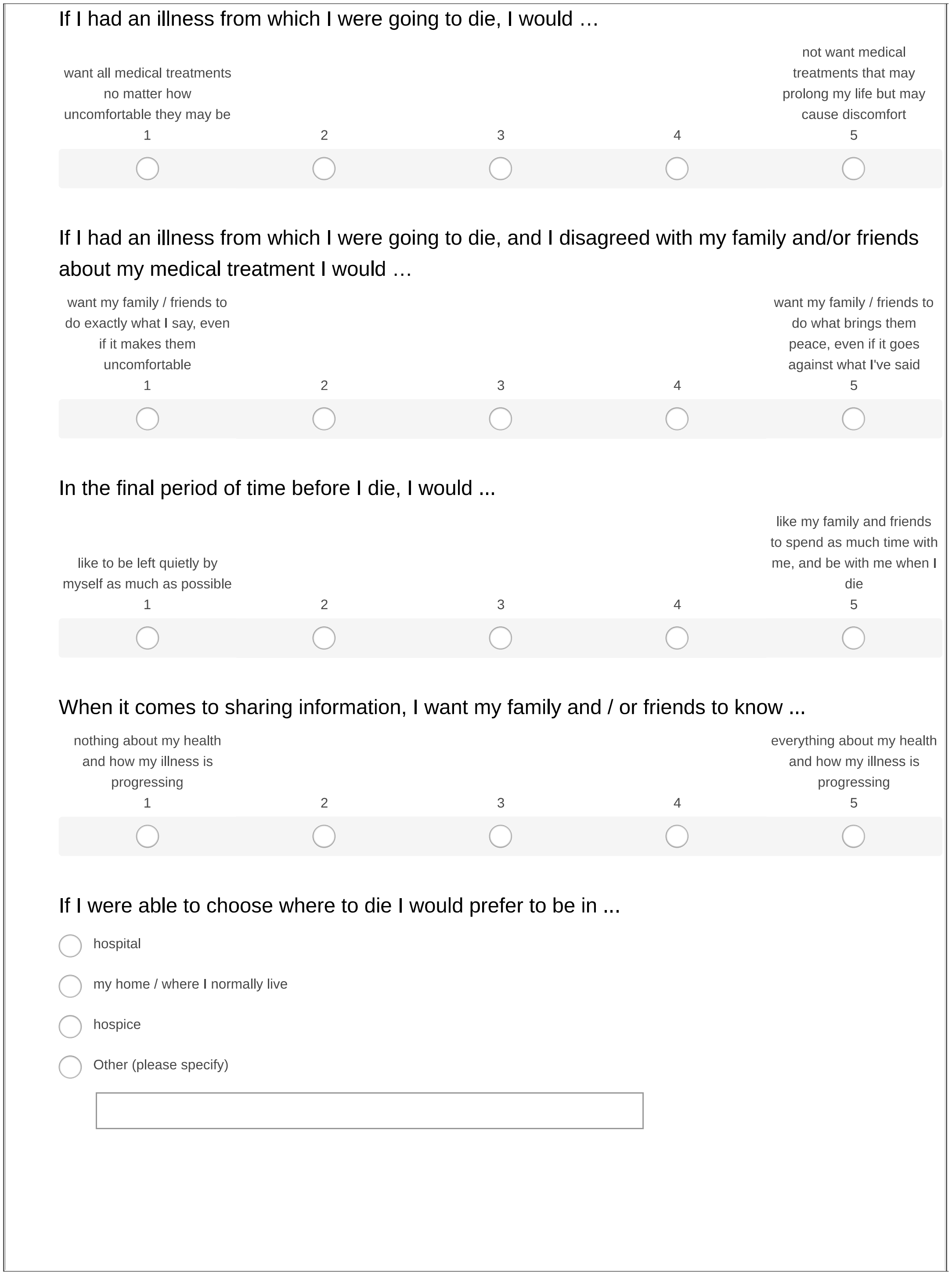
my healthcare team to do what they think is best				I want to have a say in every decision
1	2	3	4	5
○	○	○	○	○

If I had an illness from which I were going to die, I would want to …

know, approximately, how long my healthcare team think I have left to live				not know, approximately, how long my healthcare team think I have left to live
1	2	3	4	5
○	○	○	○	○

If I had an illness from which I were going to die, I would want medical treatments aimed at prolonging my life for …

as long as possible, even if my quality of life was poor				only as long as I have a good quality of life
1	2	3	4	5
○	○	○	○	○



If I had an illness from which I were going to die, I would …

want all medical treatments no matter how uncomfortable they may be				not want medical treatments that may prolong my life but may cause discomfort
1	2	3	4	5
○	○	○	○	○

If I had an illness from which I were going to die, and I disagreed with my family and/or friends about my medical treatment I would …

want my family / friends to do exactly what I say, even if it makes them uncomfortable				want my family / friends to do what brings them peace, even if it goes against what I've said
1	2	3	4	5
○	○	○	○	○

In the final period of time before I die, I would ...

like to be left quietly by myself as much as possible				like my family and friends to spend as much time with me, and be with me when I die
1	2	3	4	5
○	○	○	○	○

When it comes to sharing information, I want my family and / or friends to know ...

nothing about my health and how my illness is progressing				everything about my health and how my illness is progressing
1	2	3	4	5
○	○	○	○	○

If I were able to choose where to die I would prefer to be in ...

○ hospital

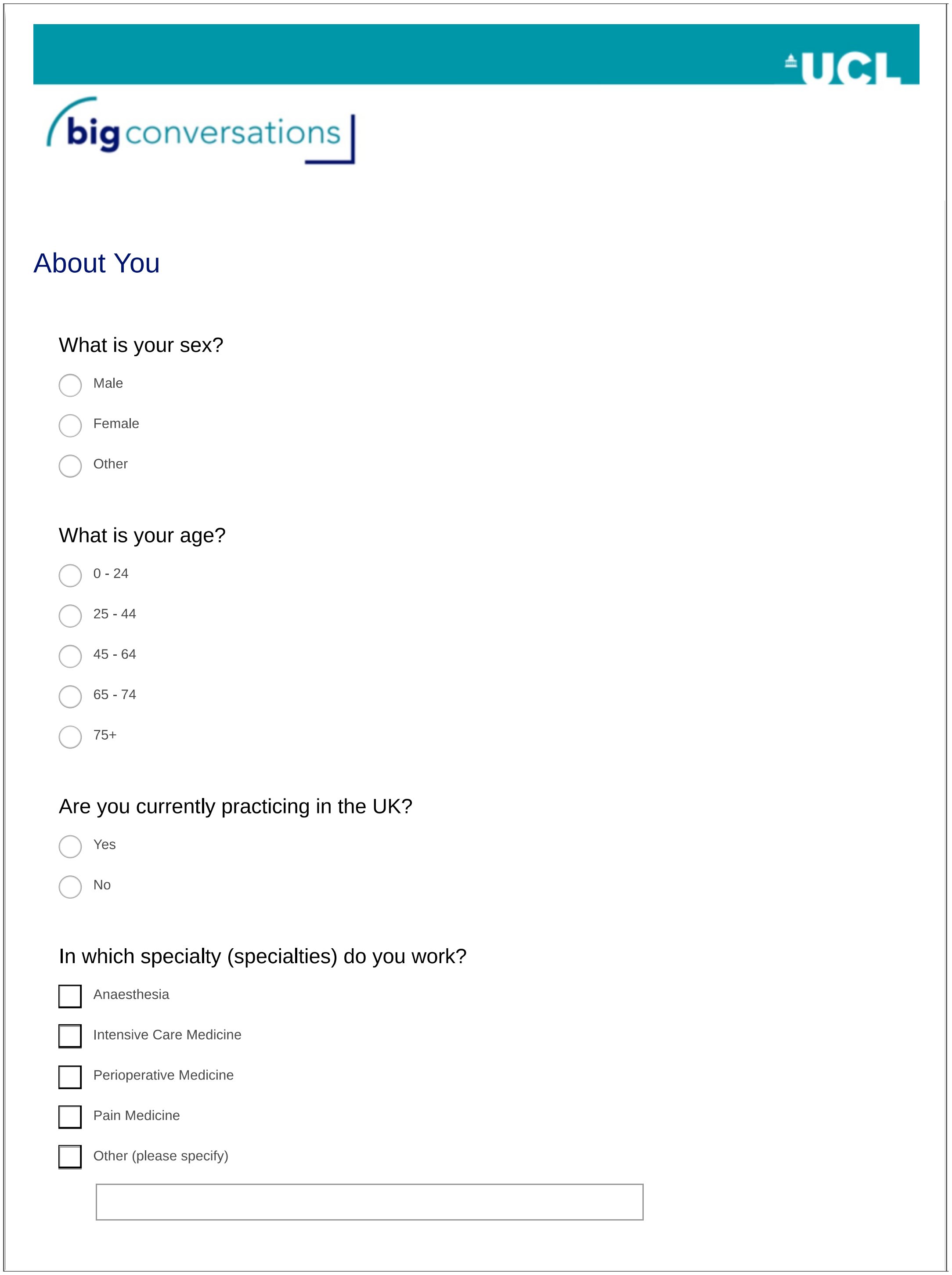
○ my home / where I normally live

○ hospice

○ Other (please specify)

The three most important things I want my friends, family and / or healthcare team to understand about my wishes and preferences for end of life care are ...

1.	
2.	
3.	



About You

What is your sex?

○ Male

○ Female

○ Other

What is your age?

○ 0 - 24

○ 25 - 44

○ 45 - 64

○ 65 - 74

○ 75+

Are you currently practicing in the UK?

○ Yes

○ No

In which specialty (specialties) do you work?

☐ Anaesthesia

☐ Intensive Care Medicine

☐ Perioperative Medicine

☐ Pain Medicine

☐ Other (please specify)

What grade is your current post?

○ Consultant

○ Staff and Associate Specialist Doctor

○ Trainee

○ Other (please specify)

How is your health in general?

○ Very good

○ Good

○ Fair

○ Bad

○ Very Bad

Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?

○ Yes, limited a lot

○ Yes, limited a little

○ No

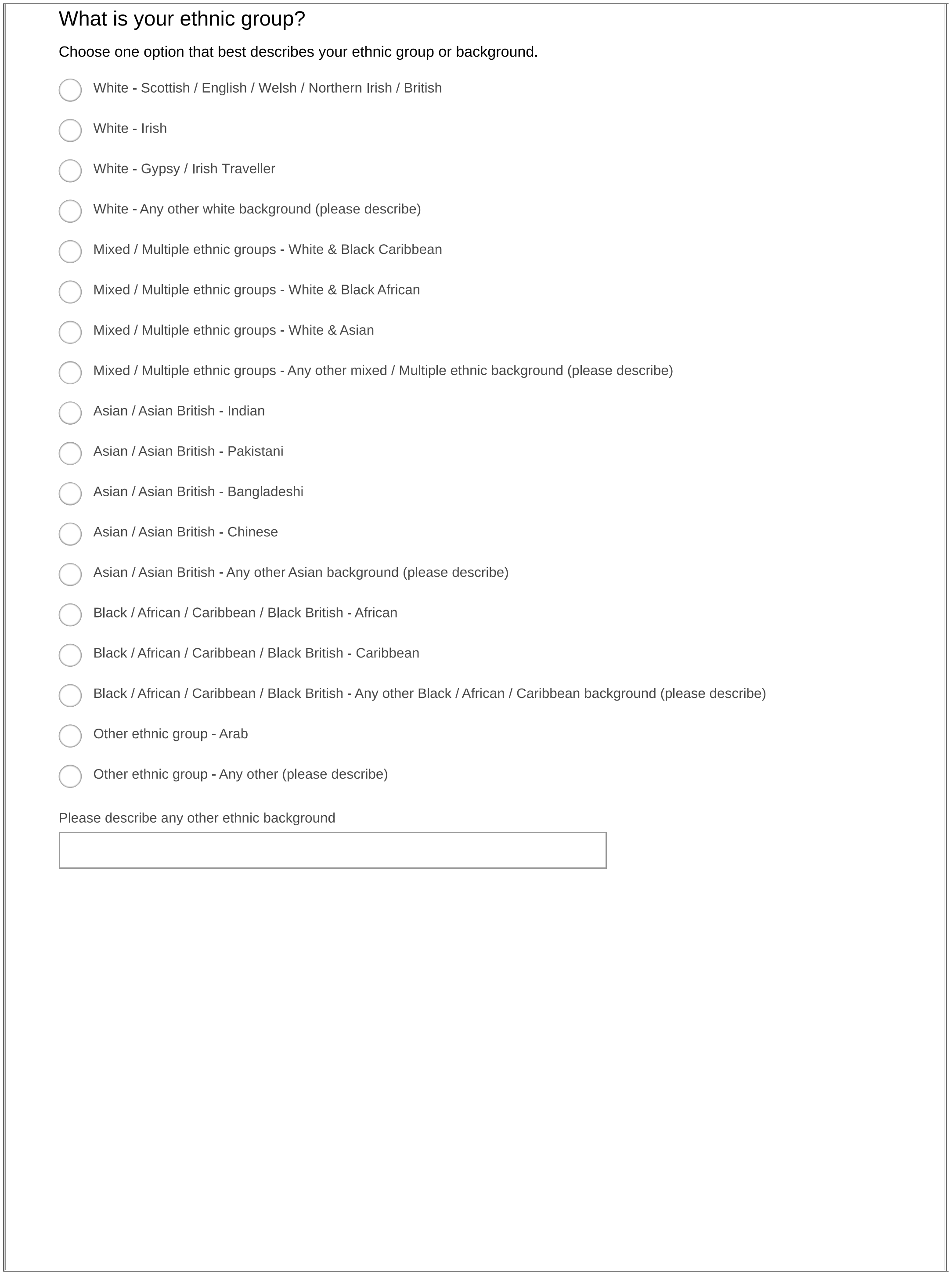
Do you look after, or give any help or support to family members, friends, neighbours or others because of either:
- long-term physical or mental ill-health / disability?
- problems related to old age?

○ No

○ Yes, 1-19 hours per week

○ Yes, 20-49 hours per week

○ Yes, 50 or more hours per week



What is your ethnic group?

Choose one option that best describes your ethnic group or background.

○ White - Scottish / English / Welsh / Northern Irish / British

○ White - Irish

○ White - Gypsy / Irish Traveller

○ White - Any other white background (please describe)

○ Mixed / Multiple ethnic groups - White & Black Caribbean

○ Mixed / Multiple ethnic groups - White & Black African

○ Mixed / Multiple ethnic groups - White & Asian

○ Mixed / Multiple ethnic groups - Any other mixed / Multiple ethnic background (please describe)

○ Asian / Asian British - Indian

○ Asian / Asian British - Pakistani

○ Asian / Asian British - Bangladeshi

○ Asian / Asian British - Chinese

○ Asian / Asian British - Any other Asian background (please describe)

○ Black / African / Caribbean / Black British - African

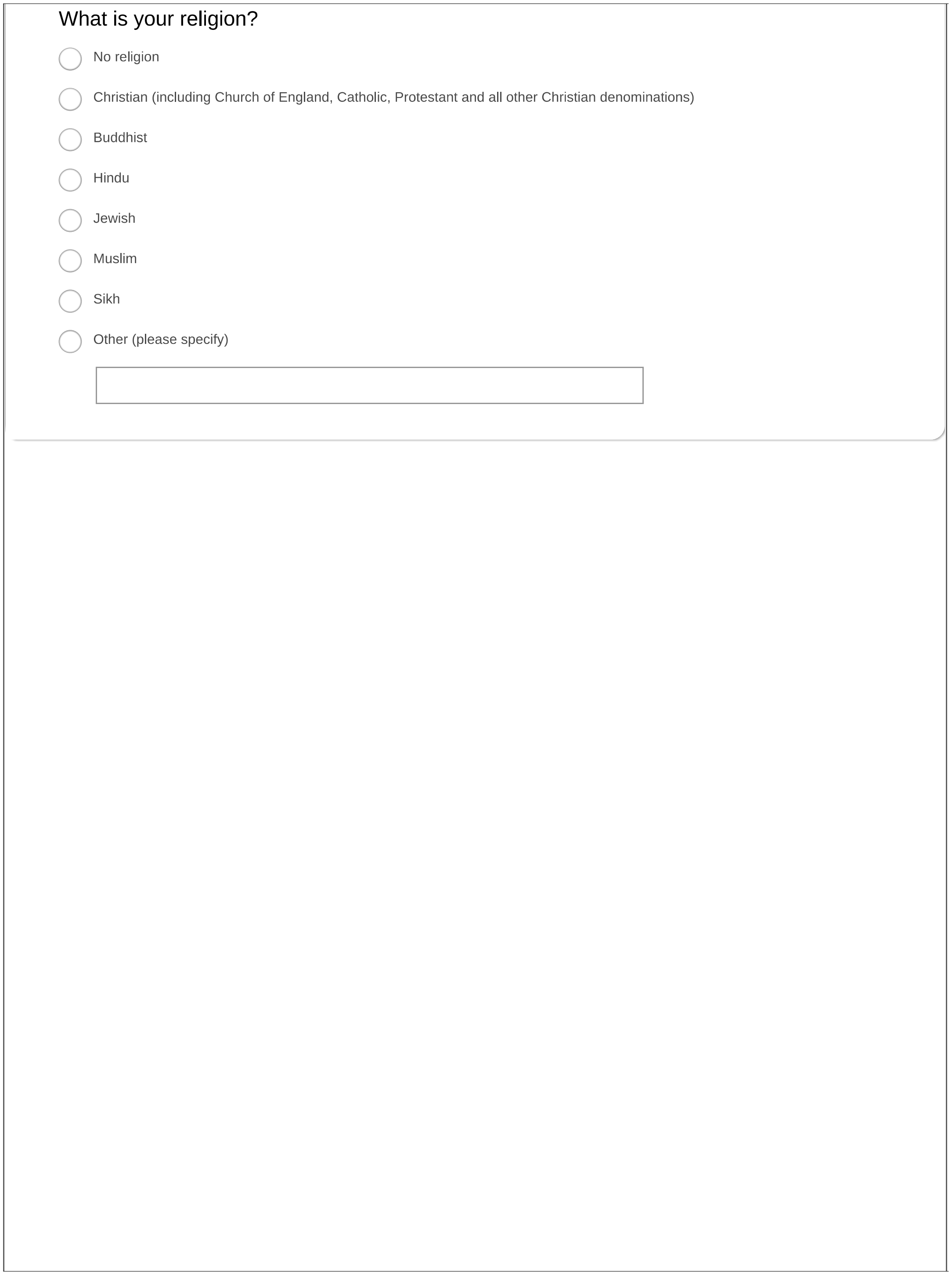
○ Black / African / Caribbean / Black British - Caribbean

○ Black / African / Caribbean / Black British - Any other Black / African / Caribbean background (please describe)

○ Other ethnic group - Arab

○ Other ethnic group - Any other (please describe)

Please describe any other ethnic background



What is your religion?

○ No religion

○ Christian (including Church of England, Catholic, Protestant and all other Christian denominations)

○ Buddhist

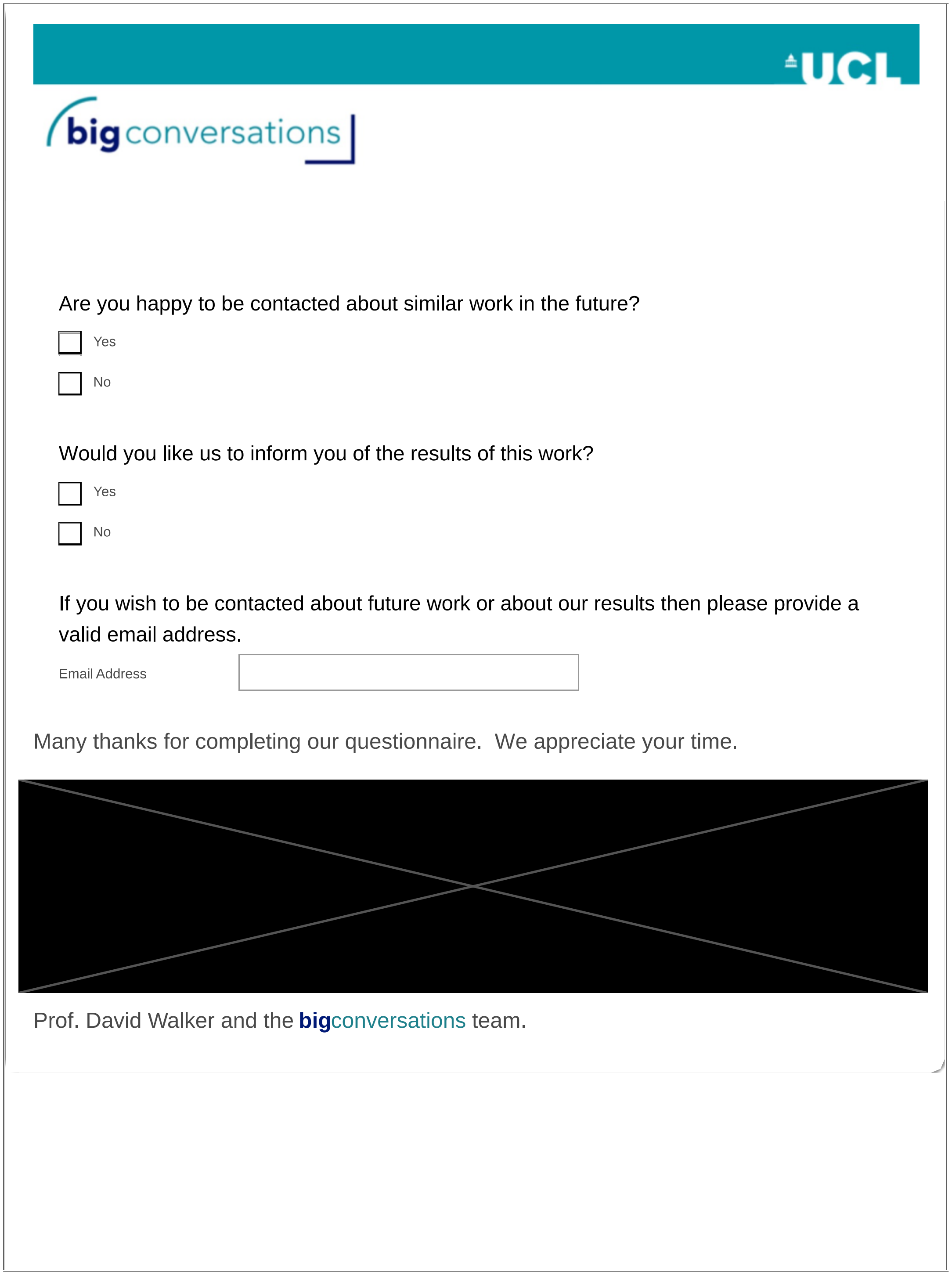
○ Hindu

○ Jewish

○ Muslim

○ Sikh

○ Other (please specify)



Are you happy to be contacted about similar work in the future?

☐ Yes

☐ No

Would you like us to inform you of the results of this work?

☐ Yes

☐ No

If you wish to be contacted about future work or about our results then please provide a valid email address.

Email Address ☐

Many thanks for completing our questionnaire. We appreciate your time.

Prof. David Walker and the **big**conversations team.

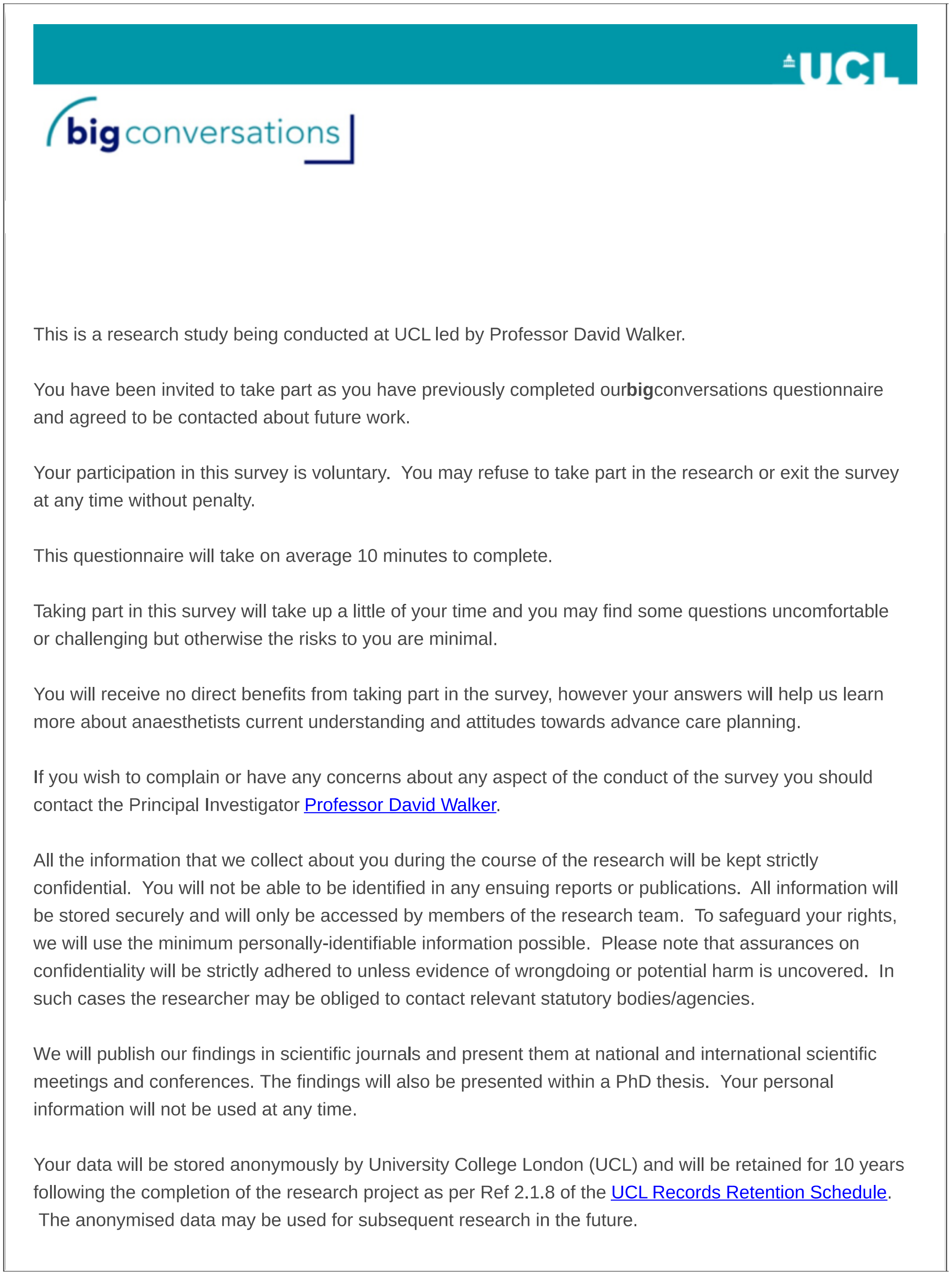
Appendix 5 Sample Search Strategy SR-KAP

((((((((knowledge AND attitude* AND (practice OR belief* OR behaviour)) OR KAP)))
AND
(survey OR questionnaire)))
AND
((((advance care plan* OR advance health care plan* OR advance health-care plan* OR advance healthcare plan* OR advance medical plan* OR advance directive* OR living will* OR advanced care plan* OR advanced health care plan* OR advanced health-care plan* OR advanced healthcare plan* OR advanced medical plan* OR advanced directive* OR advance medical direct* OR advanced medical direct* OR healthcare prox* OR health care prox* OR do-not-resuscitate order OR DNR OR dnar OR dnacpr OR do NOT attempt cardiopulmonary resuscitation OR resuscitate order OR do-not-hospitalize order OR DNH OR hospitalize order OR hospitalise order))) OR (((("Resuscitation Orders"[Mesh]) OR "Living Wills"[Mesh]) OR "Advance Directives"[Mesh]) OR "Advance Care Planning"[Mesh]))))
AND
(("Health Personnel" OR "healthcare professional" OR Physician* OR Doctor* OR Nurse*))

Appendix 6 Data Extraction Form SR-KAP

Field	**Response**
First author Surname	Free text
Year	Free text
Country	Free text
Type of article	Journal Article
	Poster Presentation
If article is a survey is it …	Quantitative
	Qualitative
	Both
Sample Size	Free text
Professional group	Nurses
	Doctors
	Both
	Other
What is the level of knowledge reported by HSCPs with regards to having EoL and ACP conversations?	Free text
What are the attitudes of HSCPs towards having ACP conversations?	Free text
What is the reported current practice of HSCPs in regard to ACP conversations?	Free text
What is the level of confidence HSCPs report in regard to having ACP conversations?	Free text
What are the necessary requirements for HSCPs to be able to have ACP conversations with patients?	Free text
Relationships between characteristics with knowledge, attitudes, confidence and practice.	Free text
Additional comments.	Free text

Appendix 7 KAP-ACP Questionnaire



This is a research study being conducted at UCL led by Professor David Walker.

You have been invited to take part as you have previously completed our**big**conversations questionnaire and agreed to be contacted about future work.

Your participation in this survey is voluntary. You may refuse to take part in the research or exit the survey at any time without penalty.

This questionnaire will take on average 10 minutes to complete.

Taking part in this survey will take up a little of your time and you may find some questions uncomfortable or challenging but otherwise the risks to you are minimal.

You will receive no direct benefits from taking part in the survey, however your answers will help us learn more about anaesthetists current understanding and attitudes towards advance care planning.

If you wish to complain or have any concerns about any aspect of the conduct of the survey you should contact the Principal Investigator Professor David Walker.

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. All information will be stored securely and will only be accessed by members of the research team. To safeguard your rights, we will use the minimum personally-identifiable information possible. Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the researcher may be obliged to contact relevant statutory bodies/agencies.

We will publish our findings in scientific journals and present them at national and international scientific meetings and conferences. The findings will also be presented within a PhD thesis. Your personal information will not be used at any time.

Your data will be stored anonymously by University College London (UCL) and will be retained for 10 years following the completion of the research project as per Ref 2.1.8 of the UCL Records Retention Schedule. The anonymised data may be used for subsequent research in the future.

Participation in the survey will be taken as implied consent.

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data and can be contacted here.

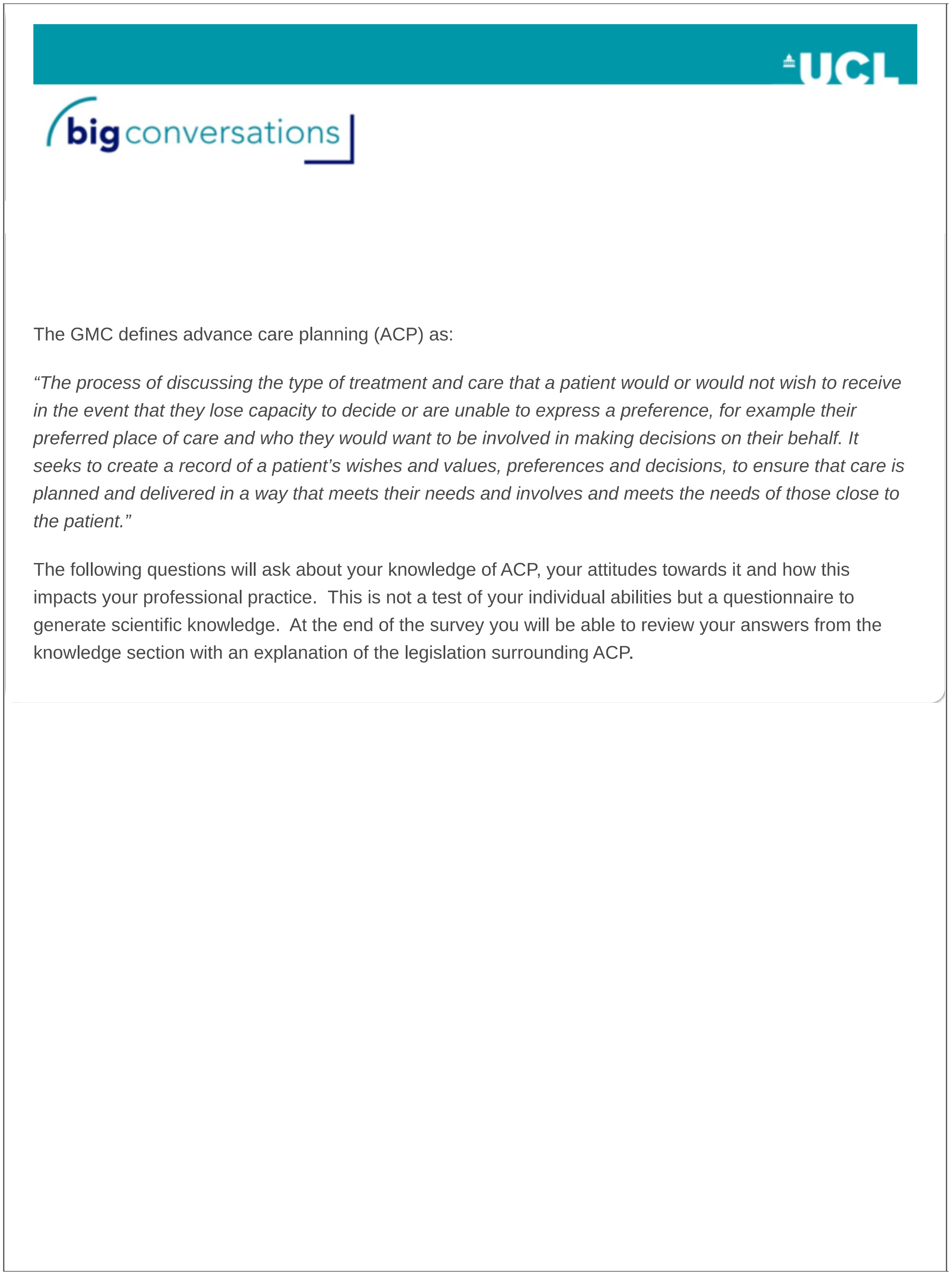
Further information on how UCL uses participant information can be found here.

The legal basis that will be used to process your personal data will be performance of a task in the public interest. The categories of personal data used will be email address, age range, gender and occupation / grade. The legal basis used to process special category personal data will be for scientific research. The categories of special category personal data used will be race, religion and health.

Your personal data will be processed so long as it is required for the research project. As soon as we are able to anonymise the personal data you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

Thank you for reading this information and for considering taking part in this research study.

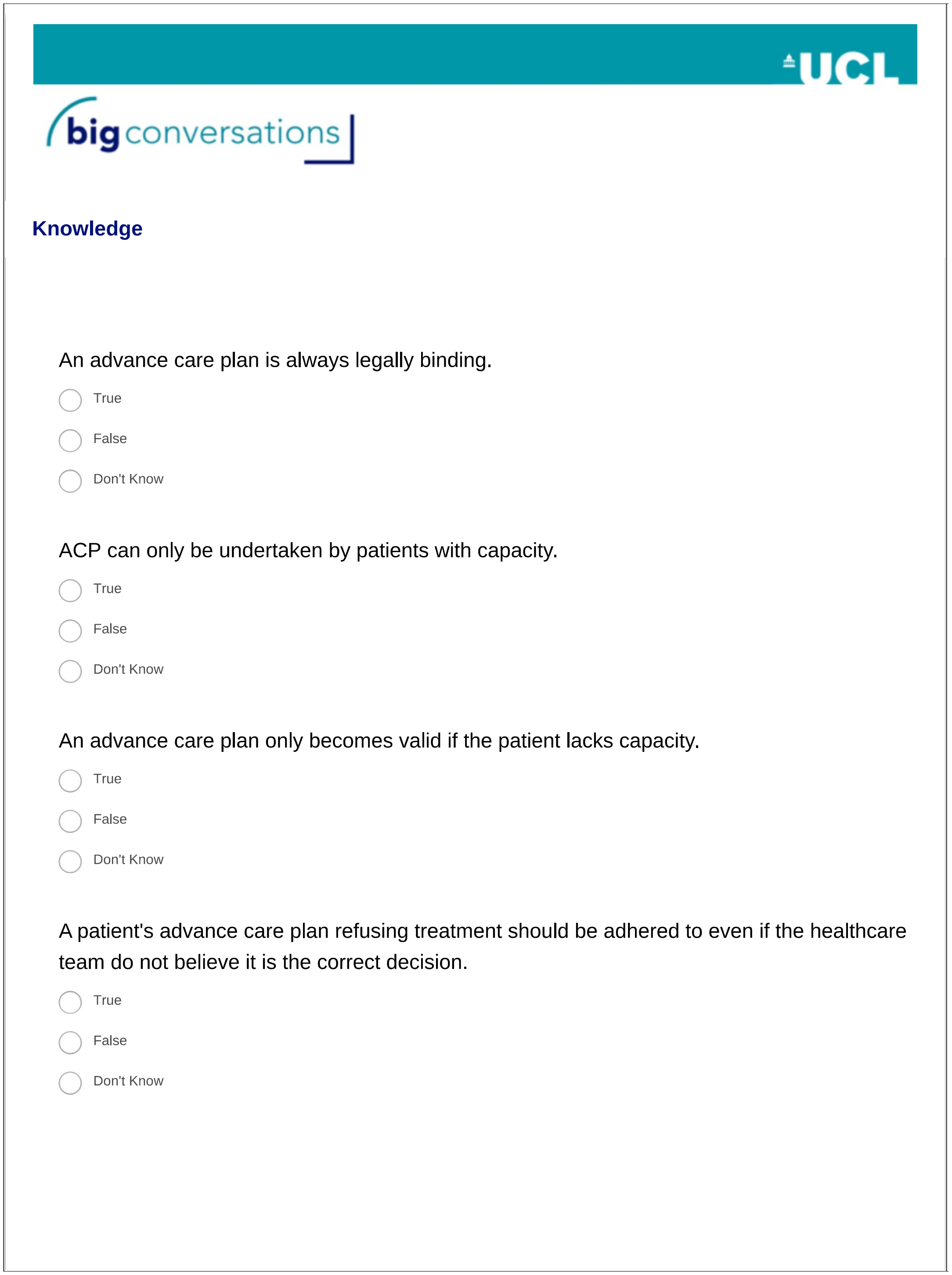
Prof. David Walker and the **big**conversations team.



The GMC defines advance care planning (ACP) as:

"The process of discussing the type of treatment and care that a patient would or would not wish to receive in the event that they lose capacity to decide or are unable to express a preference, for example their preferred place of care and who they would want to be involved in making decisions on their behalf. It seeks to create a record of a patient's wishes and values, preferences and decisions, to ensure that care is planned and delivered in a way that meets their needs and involves and meets the needs of those close to the patient."

The following questions will ask about your knowledge of ACP, your attitudes towards it and how this impacts your professional practice. This is not a test of your individual abilities but a questionnaire to generate scientific knowledge. At the end of the survey you will be able to review your answers from the knowledge section with an explanation of the legislation surrounding ACP.



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Knowledge

An advance care plan is always legally binding.

○ True

○ False

○ Don't Know

ACP can only be undertaken by patients with capacity.

○ True

○ False

○ Don't Know

An advance care plan only becomes valid if the patient lacks capacity.

○ True

○ False

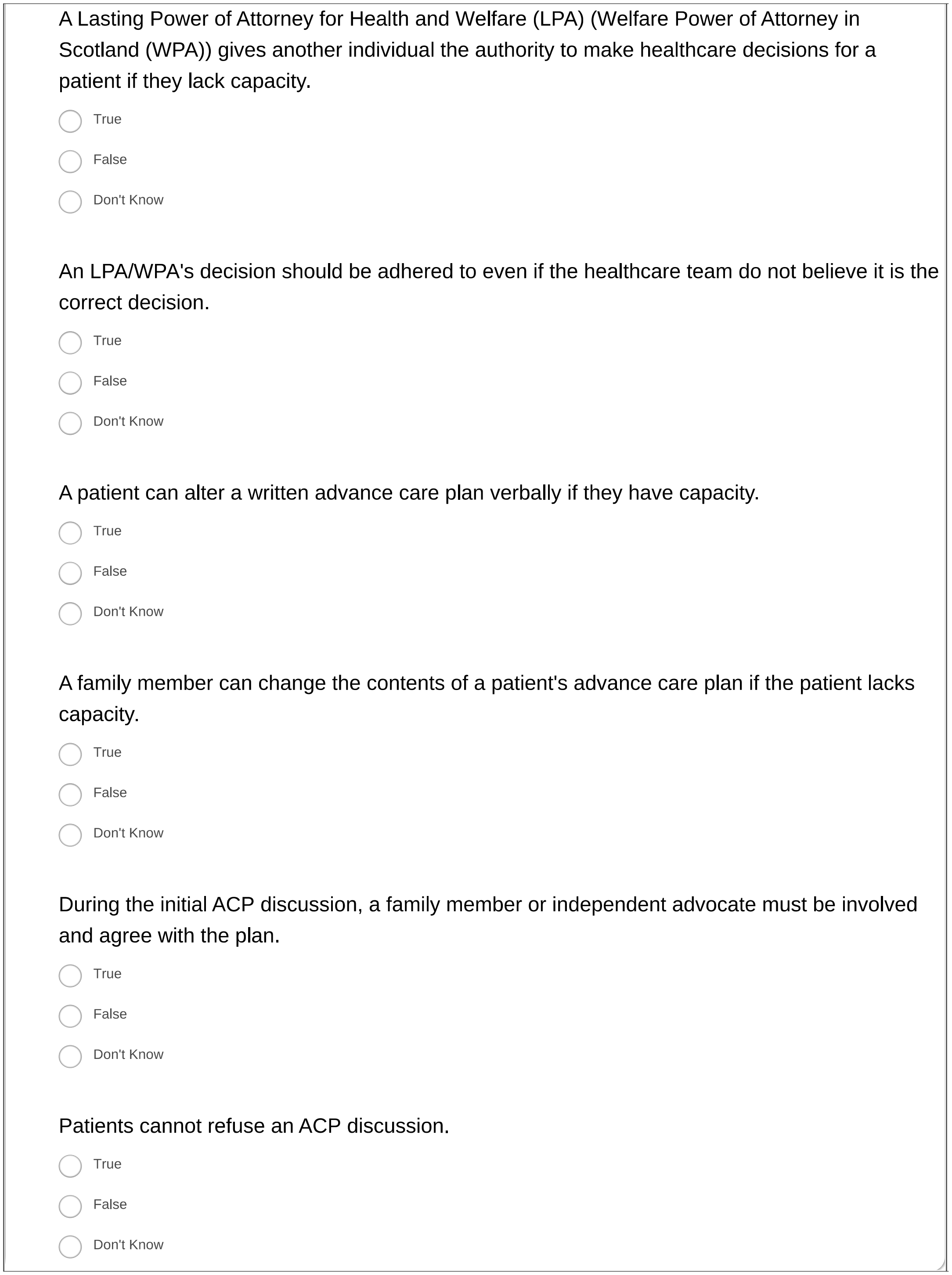
○ Don't Know

A patient's advance care plan refusing treatment should be adhered to even if the healthcare team do not believe it is the correct decision.

○ True

○ False

○ Don't Know



A Lasting Power of Attorney for Health and Welfare (LPA) (Welfare Power of Attorney in Scotland (WPA)) gives another individual the authority to make healthcare decisions for a patient if they lack capacity.

○ True

○ False

○ Don't Know

An LPA/WPA's decision should be adhered to even if the healthcare team do not believe it is the correct decision.

○ True

○ False

○ Don't Know

A patient can alter a written advance care plan verbally if they have capacity.

○ True

○ False

○ Don't Know

A family member can change the contents of a patient's advance care plan if the patient lacks capacity.

○ True

○ False

○ Don't Know

During the initial ACP discussion, a family member or independent advocate must be involved and agree with the plan.

○ True

○ False

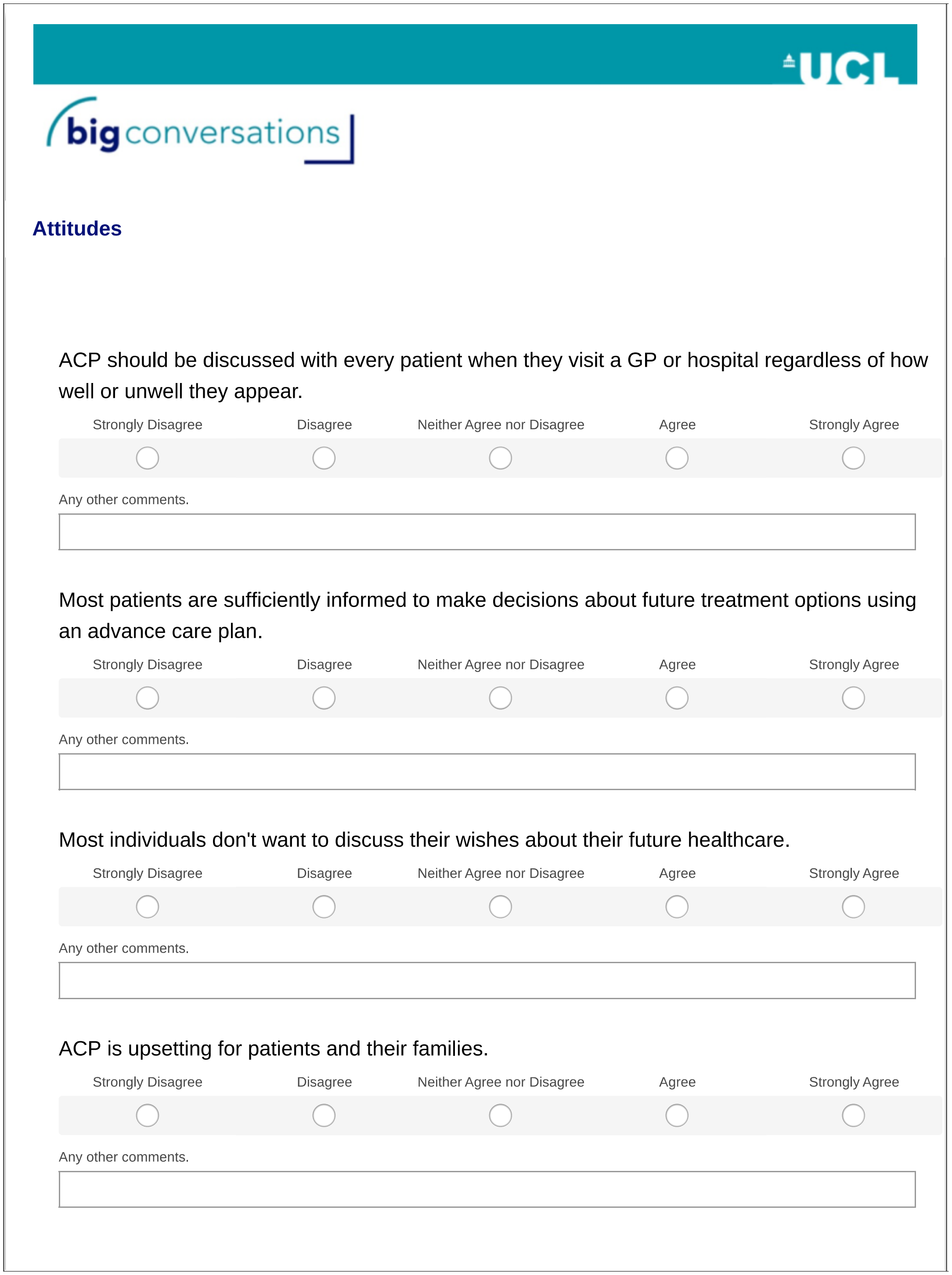
○ Don't Know

Patients cannot refuse an ACP discussion.

○ True

○ False

○ Don't Know



Attitudes

ACP should be discussed with every patient when they visit a GP or hospital regardless of how well or unwell they appear.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

Most patients are sufficiently informed to make decisions about future treatment options using an advance care plan.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

Most individuals don't want to discuss their wishes about their future healthcare.

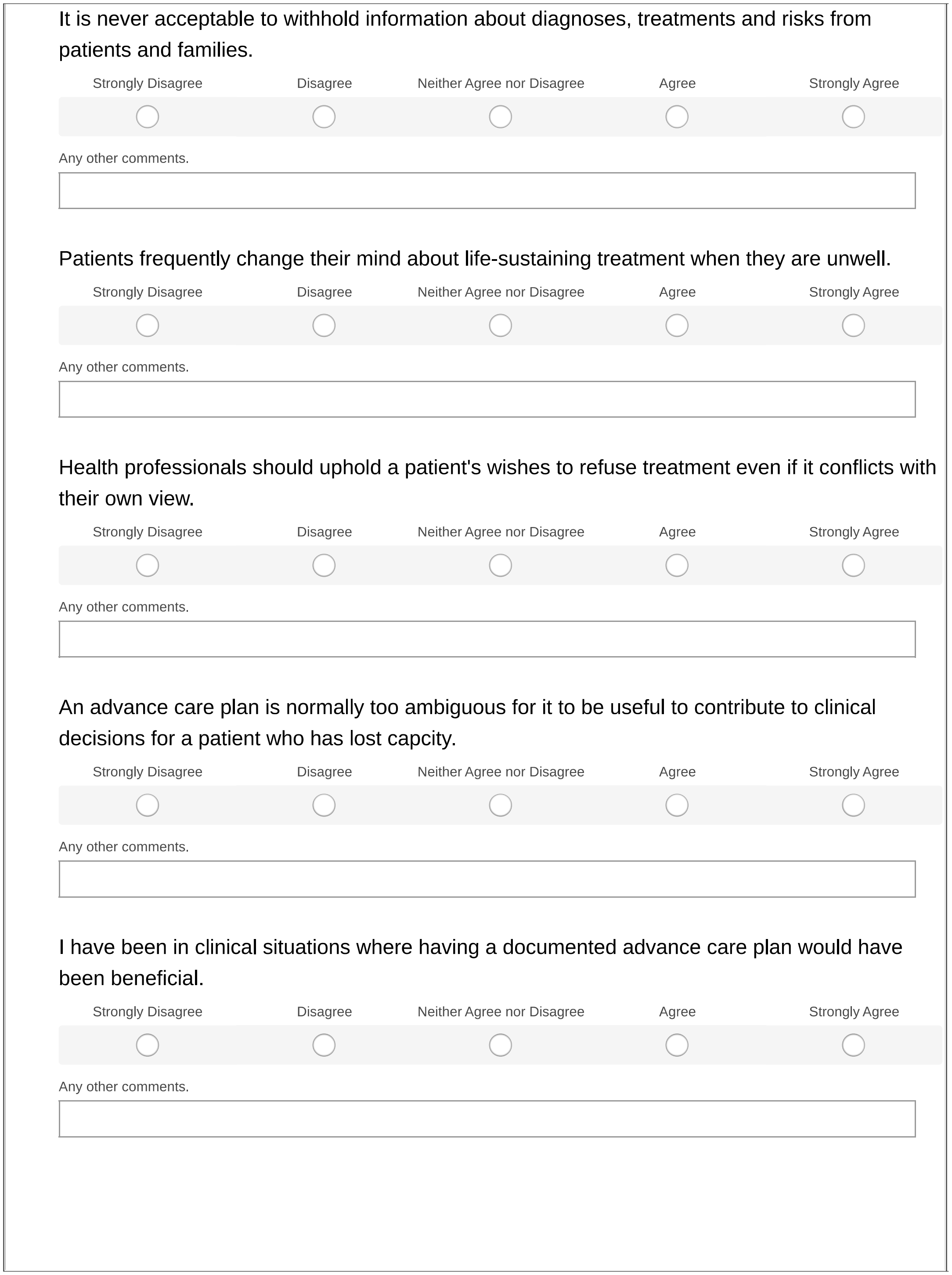
Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

ACP is upsetting for patients and their families.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.



It is never acceptable to withhold information about diagnoses, treatments and risks from patients and families.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

Patients frequently change their mind about life-sustaining treatment when they are unwell.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

Health professionals should uphold a patient's wishes to refuse treatment even if it conflicts with their own view.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

An advance care plan is normally too ambiguous for it to be useful to contribute to clinical decisions for a patient who has lost capcity.

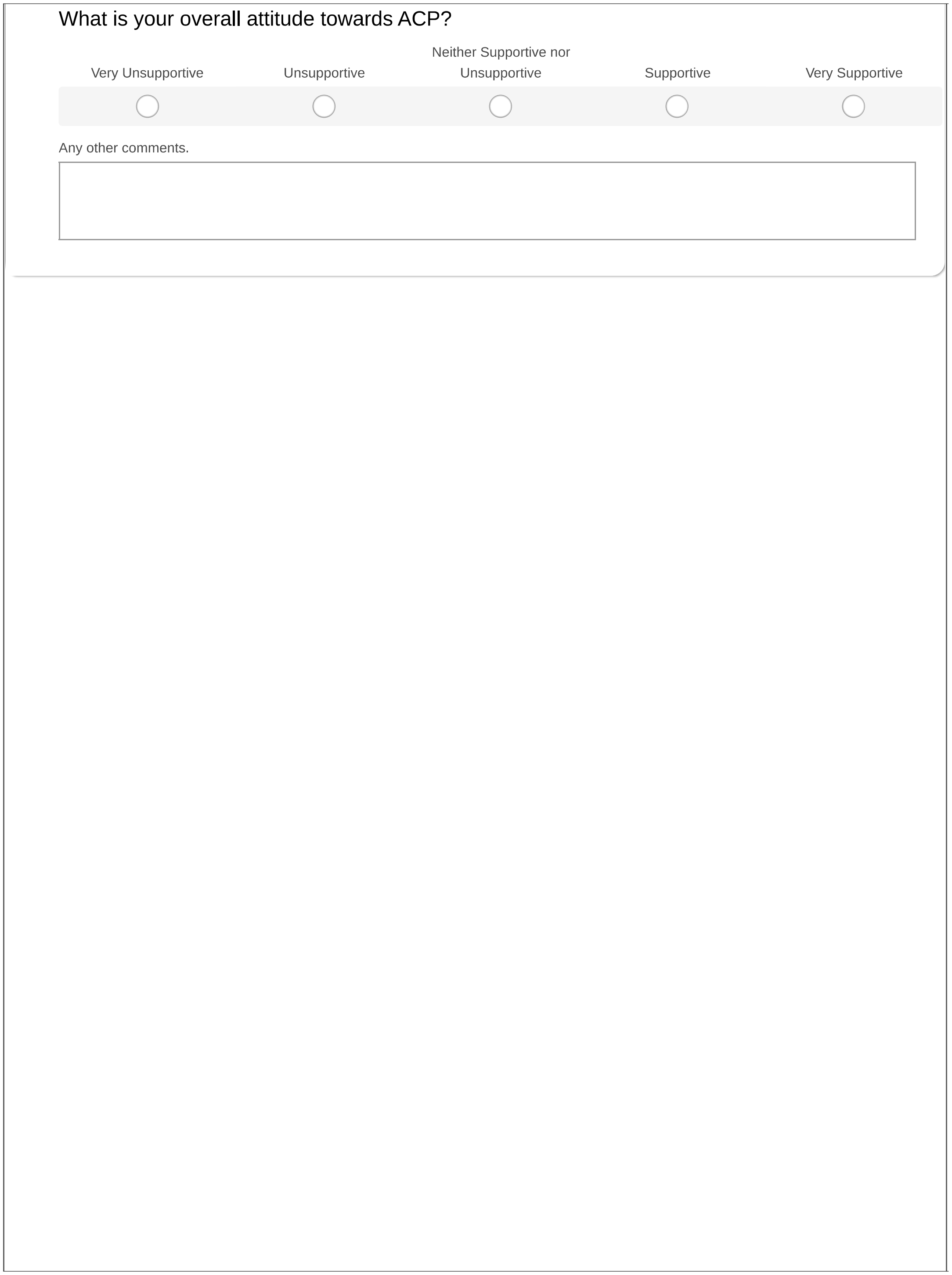
Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

I have been in clinical situations where having a documented advance care plan would have been beneficial.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

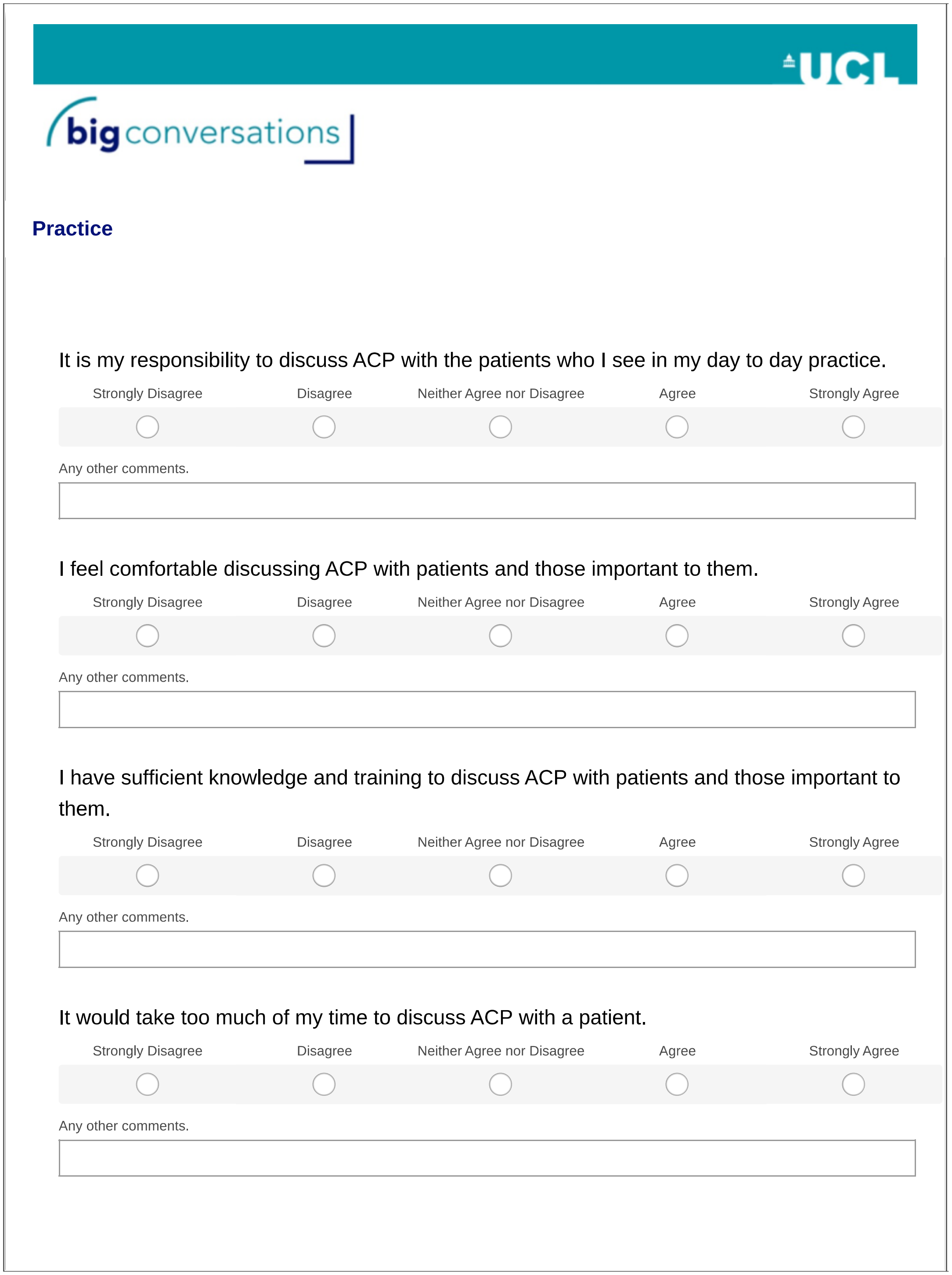
Any other comments.



What is your overall attitude towards ACP?

Very Unsupportive	Unsupportive	Neither Supportive nor Unsupportive	Supportive	Very Supportive
○	○	○	○	○

Any other comments.



Practice

It is my responsibility to discuss ACP with the patients who I see in my day to day practice.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

I feel comfortable discussing ACP with patients and those important to them.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

I have sufficient knowledge and training to discuss ACP with patients and those important to them.

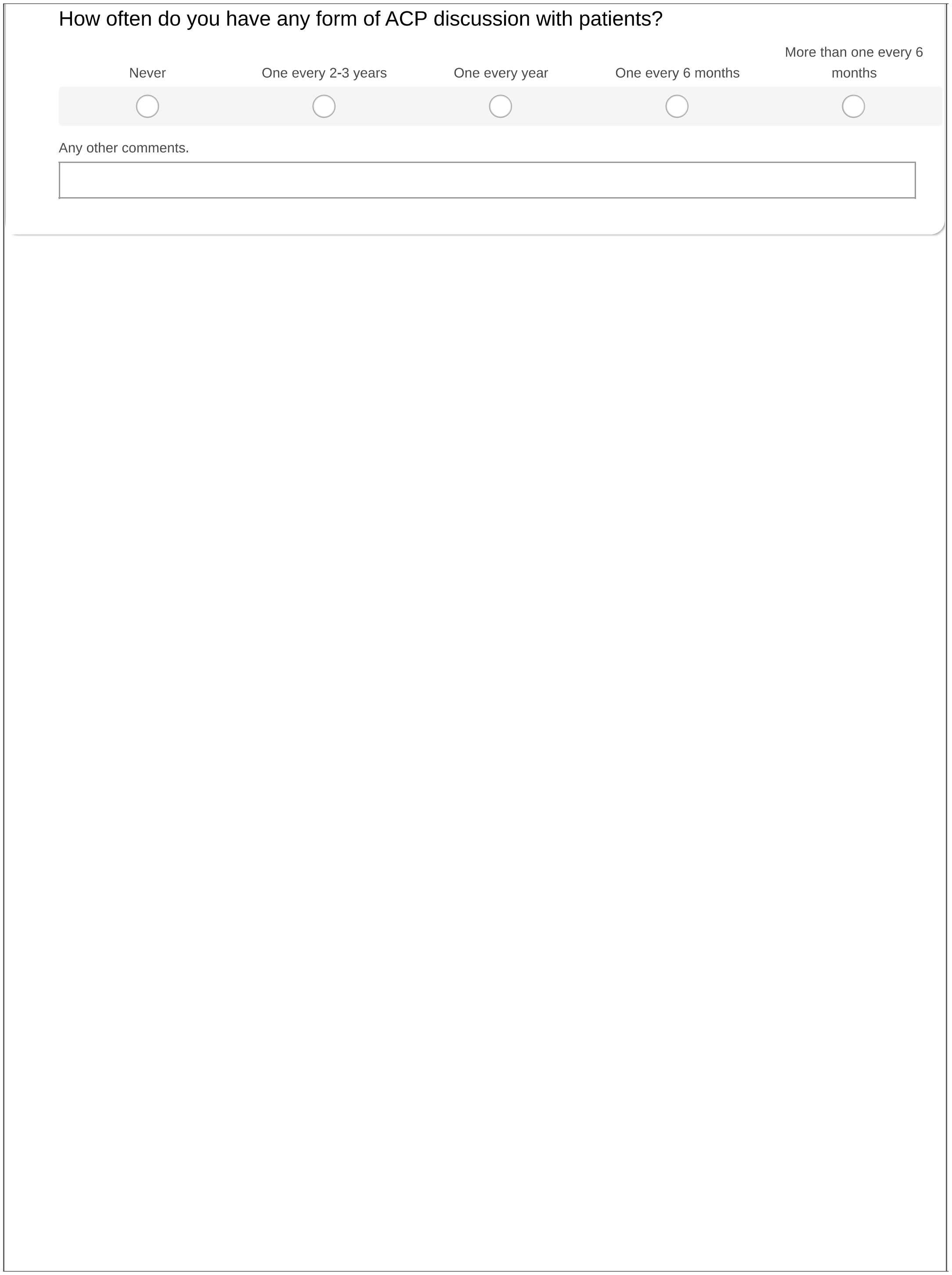
Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

It would take too much of my time to discuss ACP with a patient.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

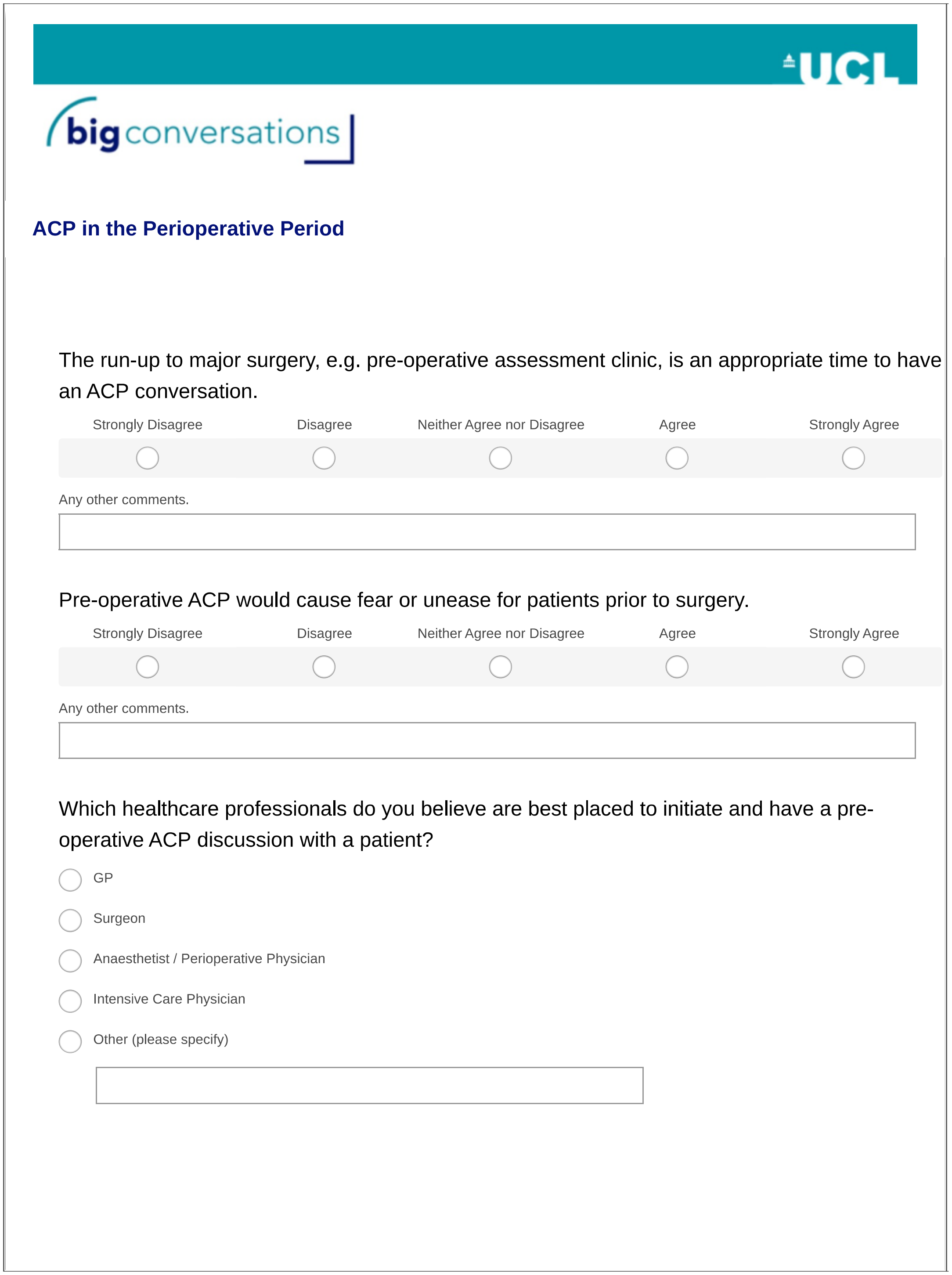
Any other comments.



How often do you have any form of ACP discussion with patients?

Never	One every 2-3 years	One every year	One every 6 months	More than one every 6 months
○	○	○	○	○

Any other comments.



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ACP in the Perioperative Period

The run-up to major surgery, e.g. pre-operative assessment clinic, is an appropriate time to have an ACP conversation.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

☐

Pre-operative ACP would cause fear or unease for patients prior to surgery.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

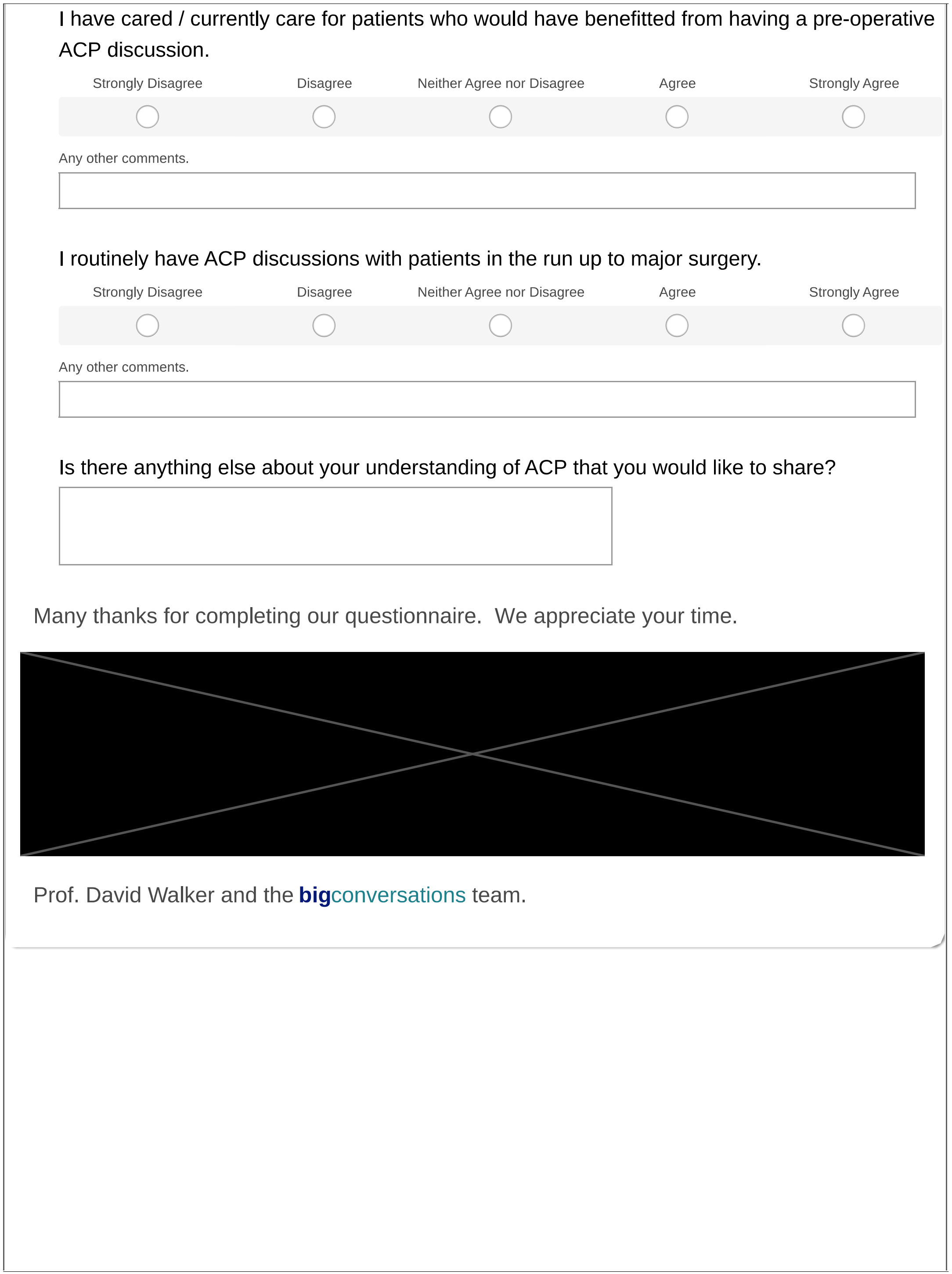
Any other comments.

☐

Which healthcare professionals do you believe are best placed to initiate and have a pre-operative ACP discussion with a patient?

○ GP
○ Surgeon
○ Anaesthetist / Perioperative Physician
○ Intensive Care Physician
○ Other (please specify)

☐



I have cared / currently care for patients who would have benefitted from having a pre-operative ACP discussion.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

I routinely have ACP discussions with patients in the run up to major surgery.

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
○	○	○	○	○

Any other comments.

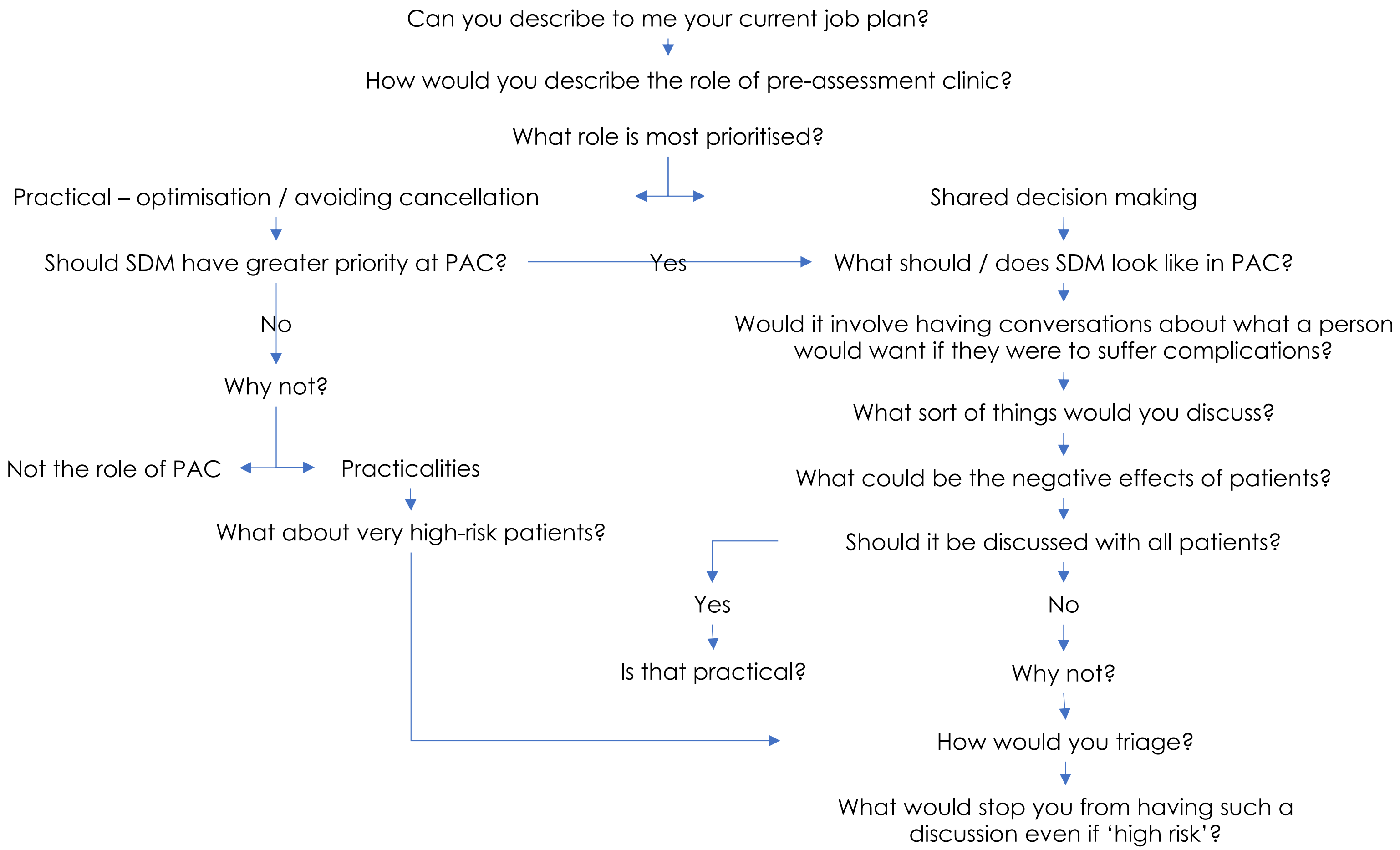
Is there anything else about your understanding of ACP that you would like to share?

Many thanks for completing our questionnaire. We appreciate your time.

[redacted]

Prof. David Walker and the **big**conversations team.

Appendix 8 Interview Guide QSE



What would be the aim of these discussions?

↓

What would your role be in these discussions?
- Provide information / Give opinion or advice

↓

In your experience are most patients able to understand this information and make these decisions?

↓

Do you think patient's are willing to have these discussions?

↓

How long do you think this sort of discussion would take on average?

↓

Would you have a discussion like this on the morning of surgery?

↓

What about in emergency cases?

↓

Why do you think it is different in emergency cases?

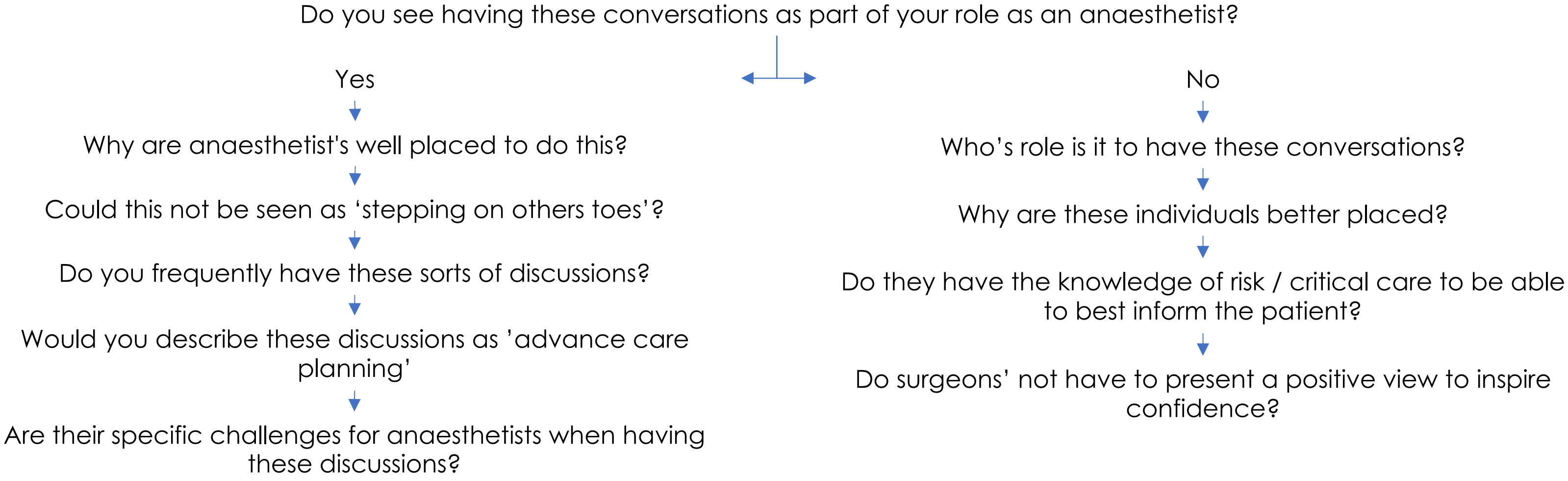
Have you ever had any formal training to have these discussions?

↓

Was it / would it have been useful?

↓

Can you really be 'trained' to do this sort of thing?



Do you see having these conversations as part of your role as an anaesthetist?

Yes

Why are anaesthetist's well placed to do this?

Could this not be seen as 'stepping on others toes'?

Do you frequently have these sorts of discussions?

Would you describe these discussions as 'advance care planning'

Are their specific challenges for anaesthetists when having these discussions?

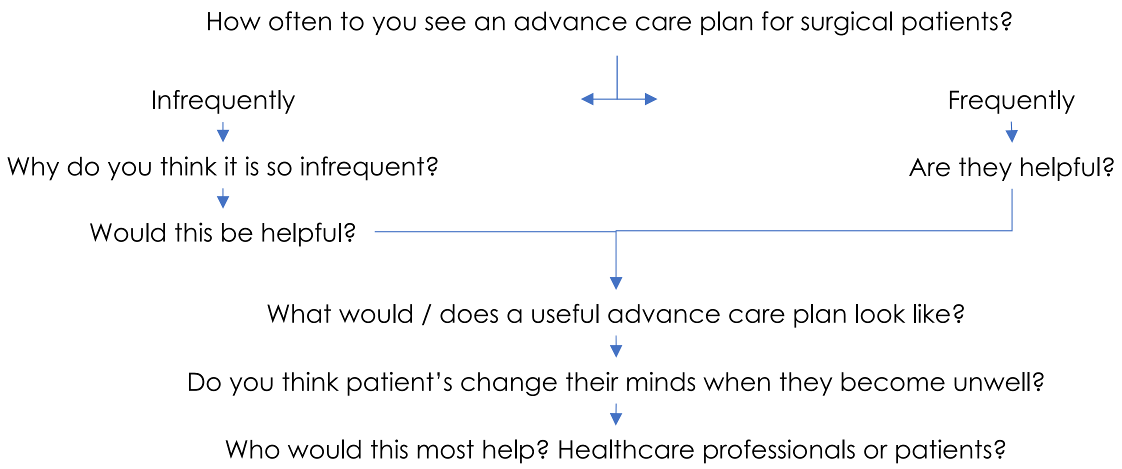
No

Who's role is it to have these conversations?

Why are these individuals better placed?

Do they have the knowledge of risk / critical care to be able to best inform the patient?

Do surgeons' not have to present a positive view to inspire confidence?



How often to you see an advance care plan for surgical patients?

Infrequently

Why do you think it is so infrequent?

Would this be helpful?

Frequently

Are they helpful?

What would / does a useful advance care plan look like?

Do you think patient's change their minds when they become unwell?

Who would this most help? Healthcare professionals or patients?

Appendix 9 Fieldnote Template QSE

Observation Site: **Observation Date:** **Start Time:** **End Time:**

Description	**Reflections**

Appendix 10 Publications

Blackwood DH, Vindrola-Padros C, Mythen MG, Columb MO, Walker D. A national survey of anaesthetists' preferences for their own end of life care. British Journal of Anaesthesia. Elsevier Ltd; 2020; 125(6):1088–98. Available from: https://doi.org/10.1016/j.bja.2020.07.055

Cosgrove J, Baruah R, Bassford C, **Blackwood D**, Pattison N, White C. Care at the End of Life: A guide to best practice, discussion and decision-making in and around critical care. *The Faculty of Intensive Care Medicine*. London; 2019. Available from: https://www.ficm.ac.uk/sites/default/files/ficm_care_end_of_life.pdf

Blackwood DH, Walker D, Mythen MG, Taylor RM, Vindrola-Padros C. Barriers to advance care planning with patients as perceived by nurses and other healthcare professionals: A systematic review. J Clin Nurs. 2019; 28(23–24):4276–97. Available from: https://doi.org/10.1111/jocn.15049

Blackwood DH, Vindrola-Padros C, Mythen MG, Walker D. Advance-care-planning and end-of-life discussions in the perioperative period: a review of healthcare professionals' knowledge, attitudes, and training. Br J Anaesth. 2018; 121(5):1138–47. Available from: https://doi.org/10.1016/j.bja.2018.05.075

Blackwood D, Santhirapala R, Mythen M, Walker D. End of life decision planning in the perioperative setting: the elephant in the room? Br J Anaesth. 2015; 115(5):648–50. Available from: https://doi.org/10.1093/bja/aev209