

Improving communication between health care professionals and patients in the NHS in England

Findings of a systematic evidence review
and recommendations for an action plan

Foreword

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In 2016, when I wrote *The Long and Winding Road*, the reception to its publication was muted. The case it put forward was simple: improvements in communication between healthcare professionals and patients were likely to improve the quality of patient care and to reduce its cost. The patient *and* the taxpayer would benefit. The first part of the case was not difficult to make. Indeed, it had been made many times before. But the second part was more innovative and apparently less easily received. It was almost as though there was some embarrassment about accepting a spend-to-save case in this aspect of public policy. The most that critics could say was that there was debate to be had about which element of healthcare should be the focus for the preferred investment. Nobody took issue with the core argument, just with its emphasis.

A year passed and it seemed the report had lost its traction. To revive interest in the topic, I pressed the case with Sir Simon Stevens, CEO of NHS England, urging him to provide a substantive response to the report. Here, after all, was an opportunity to improve healthcare and to save money, all at a time when the NHS was under exceptional budgetary pressure. But I was conscious that Sir Simon receives countless proposals for new expenditure plans. In that context, I congratulate him on his response. He commissioned a detailed study into how this invest-to-save project could be taken forward.

Two years on we have in this report the results of the study commissioned by Sir Simon. The report has weighed the evidence and has been subject to rigorous review at each stage of its development. Its main recommendation is investment in a single, strategic intervention: training clinicians to have conversations with patients nearing the end of their lives about what these patients want from their care. The patient benefits by themselves make a powerful case for introducing these conversations as routine practice across NHS Acute Hospital Trusts. The associated health system benefits quantified in the report make that case compelling. There will be discussion about the precise level of financial savings to be realised. But the return on investment estimated in this report is on such a scale, there cannot be any serious doubt that a positive return will be secured.

We all know that studies by themselves do not make a jot of difference to patients' experience of healthcare, nor do they save a pound of public expenditure. So I commend the recommendations of this systematic study to Sir Simon and his colleagues for immediate implementation. The time for debate on the focus of investment is over, the time for action is now. Patients taxpayers will benefit.

Executive summary

Introduction

1. Over the past 20 years a wealth of studies has shown the positive effects of interventions to improve communication between clinicians and patients. Studies from around the world demonstrate that effective patient/clinician communication can improve patients' experiences and health outcomes.
2. Building on this evidence base and the 2016 report *A Long and Winding Road*, NHS England¹ convened a Clinical Communications Steering Group (the Steering Group²) in 2018 to find out:
 - Whether this evidence now supports systematic investment in improving clinician/patient communication across NHS Acute Trusts in England
 - If so, what particular intervention or interventions to target.
3. To answer these questions, the **Steering Group commissioned a systematic review of the international literature on interventions to improve clinician-patient communication.** Its aim was to identify interventions that have previously demonstrated a positive difference to patient experience and clinical outcomes, while also reducing financial demands on the health system. The options identified needed to be interventions that policy makers, commissioners and service managers across the NHS could replicate accurately, with a reasonable return on their investment and at a manageable level of implementation risk.
4. **The systematic review has been undertaken by [SQW](#), an independent research and consultancy organisation.** This report has been prepared by SQW and presents key findings from the systematic review and the evidence base which supports the case for investing in improving communication between clinicians and patients in the NHS.
5. Of the options identified by the literature review, **this report recommends that NHS England & NHS Improvement initially invest in a single intervention: introducing patient-centred goals of care conversations** with patients presenting in Acute Medical Units (AMUs) and Surgical Assessment Units (SAUs) who are at risk of dying in the next 12 months and/or are at risk of serious clinical deterioration and death during their presentation.
6. These voluntary conversations between patients and a clinical member of staff take place within 48 hours of the patient's admission. In the course of the conversation: the clinician gives the patient information about their condition and treatment options; the patient has the opportunity to express their particular values, goals, priorities and treatment preferences; the clinician hears and respects these values, priorities and preferences; and the clinician records them in a single care planning document. This document would be created during the first conversation and updated as needed during subsequent conversations. Patients and their

¹ Since merged with NHS Improvement to form NHS England & NHS Improvement.

² See Acknowledgements for members.

families keep a paper copy of the original plan and any updates. Staff also record the decisions and any other key outcomes of the conversations in their organisation's electronic system.

7. The evidence indicates that **introducing these conversations as routine clinical practice will significantly improve the experience of patients nearing the end of their lives, enhancing their quality of life while reducing their requirements for critical care.** This reduction in demand for hospital care means the costs of introducing goals of care conversations are more than outweighed by the likely savings.
8. The modelling of the potential **cost savings presented in this report shows them to represent an estimated potential saving to the national healthcare system of £502million per year (2019/20 values)** when all NHS Acute Trusts have embedded goals of care conversations as normal practice.
9. **The combination of significant patient benefits and lower hospital costs makes a compelling case for introducing goals of care conversations** with patients nearing the end of their lives across the NHS. This study recommends extending the practice nationally and includes an action plan for a national rollout. An NHS Trust is currently undertaking a proof of concept programme to consider the viability of further rollout.
10. The study's advisory group also recommends a subsequent rollout of the intervention to respiratory, cardiology and elderly care wards within acute providers. This is estimated to yield a further £59million per annum of potential savings (2019/20 values).

Research and collaboration supporting goals of care conversations

The recommended intervention draws on research studies that examined the impact of three personalised end of life care planning interventions. It blends elements from each of these into a single, cohesive care planning conversation and educational package.

The recommended structure and implementation plan for the conversations have been refined in collaboration with an advisory group comprising academic and clinical experts in end of life care and patient-clinician communication.

The core elements of this recommended approach are consistent with the Liverpool Care Pathway review of 2013³ and subsequent end of life care audits undertaken by the Royal College of Physicians (RCP)^{4 5}. This recommended approach should be considered in conjunction with the ongoing revisions to the General Medical Council's consent guidance.

Patient benefits from goals of care conversations

11. Personalised care planning can bring substantial benefits to patients and their families. Evidence suggests that as a result of having care planning conversations:

³ Findings of that review published [here](#).

⁴ The latest of which - *End of Life Care Audit: Dying in Hospital* - is published [here](#).

⁵ The Liverpool Care Pathway review and RCP audits did not feature in the international literature reviewed during this study, but the approach's consistency with each has been advised by this study's advisory group.

- **Patients' wishes are better recorded and adhered to by staff providing their care.** In line with their expressed wishes, patients who undertake personalised care planning are more likely to receive palliative care instead of curative care, are less likely to receive unwanted invasive treatments, and are more likely to die at home rather than in hospital (evidence suggests show more patients would prefer to die at home than currently do).
- **Patients' satisfaction with their care improves.** Patients can experience improvements in their quality of life and wellbeing, and less depression and anxiety. Family satisfaction is also demonstrated to improve, whilst stress, anxiety and depression are reduced in surviving relatives.
- **Patients may also live longer.** Evidence shows an association between personalised care planning and lower patient mortality rates.

Healthcare system benefits

12. There is strong evidence that holding goals of care conversations with patients who have life-limiting/terminal illnesses reduces **the time these patients spend in hospital in the 12 months before they die**. This kind of care planning can also reduce emergency admissions and calls for emergency teams to attend to patients already in hospital. In addition, end of life discussions have been associated with reduced invasive medical care near death, such as ventilation and resuscitation.
13. The costs of introducing goals of care conversations into hospitals are more than outweighed by savings from the associated reduction in time spent in hospital. The net estimated cost saving for an average NHS Acute Trust from introducing goals of care conversations with these patients would be £3million per year, representing a total annual cost saving to NHS hospitals of £502million.
14. Once goals of care conversations in AMUs and SAUs have become routine and their benefits demonstrated, they can be introduced into other areas of care in a second phase of the national rollout. This study's advisory group recommends the approach could be **extended to respiratory, cardiology and elderly care wards within acute providers**.
15. We estimate that this wider rollout of goals of care planning could generate a further total cost saving to NHS hospitals of £59 million per year (2019-20 values).
16. None of the studies reviewed looked at whether patients' lower use of secondary care led to increased use of social, hospice, community or primary care services. Potential costs to these services could therefore not be accounted for in our cost/savings analysis of the intervention. However, the scale of the net savings to the NHS noted above is likely to offset a modest rise in utilisation of other services. Reducing patient bed days during end of life may also give acute services more capacity to deal with other pressures, potentially allowing them to increase throughput on elective operations and/or improve waiting time performance.
17. Any knock-on effects on demand, costs and capacity elsewhere in the health and social care system need to be captured and monitored in the continuing review of the impact of introducing goals of care conversations.

Implementing the introduction of goals of care conversations

18. Introducing goals of care conversations in AMUs and SAUs with all admitted patients identified as being at increased risk of serious clinical deterioration and death during their presentation and/or at risk of dying within the next 12 months requires a number of actions at national and local levels.

Actions for NHS Acute Trusts

19. For NHS Acute Trusts, the headline actions are setting up regular training for the appropriate staff, planning for the impact that delivering the intervention will have on resources⁶, and making sure systems for storing plans and monitoring and evaluating this intervention are adequate:
- **Setting up regular training for the AMU/SAU staff who conduct goals of care conversations.** These will be core medical trainees (CT2), specialist registrars (ST2), charge nurses, advanced nurse practitioners and band 6-7 physiotherapists or occupational therapists. Based on advisory group steer, we recommend that these staff members would all need to attend a 2-day modular training course, plus a follow up half-day session 3-6 months later. Training would be repeated annually, to make sure new staff are familiar with the principles and processes.
 - Alongside training for the clinicians who hold the goals of care conversations with patients, **consultants and matrons on AMU/SAU rotas would require an introductory session** to understand the need for goals of care conversations and how to listen to and act on the information they yield. This single training session is planned to take two hours.
 - **Planning for the impact on resources.** Trusts will need to estimate the number of patients eligible for goals of care conversations, to allocate the right amount of clinicians' time to conducting conversations. On average, about 24% of all patients admitted to AMUs/SAUs will be eligible. Holding a goals of care conversation takes about 30 minutes of additional clinical time per patient. Discharged patients would need a second 30-minute conversation to revise their plan before they leave the hospital.
 - **Maintaining systems for managing care plans and for monitoring delivery.** Trusts' existing planning documents and record keeping systems should be capable of capturing the level and detail of information needed for storing and amending care plans, for local and national care planning, and for monitoring/evaluation purposes. A member of administrative staff at each Trust would need to collate, standardise and submit the relevant data to national project management and evaluation teams.

⁶ Some actions, such as procuring training sessions, are assumed to necessitate a cash spend. Other actions, such as clinicians' time to hold goals of care conversations and attend training, will require dedicated resourcing but are not assumed to be an 'additional' cost requiring cash outlay by Trusts. Our cost/savings analysis in the main body of this report only includes the cost of actions requiring a cash spend/incurred an additional cost. All estimated costs are detailed in full in Annex C of the main report.

Actions at the national level

At a national level, the main actions required are as follows:

- **Establishing ‘proof of concept’ in one Trust** to generate implementation learning and evidence of impact to inform wider roll-out.
- **Establishing a ‘development group’** with appropriate skills and expertise to design a standard training programme. This group will play a key role during the first 3-6 months of developing the intervention and have less input thereafter. The expertise and skills needed by the development group are expected to include:
 - Clinical expertise in and knowledge of end of life care and AMUs/SAUs during phase one, and in elderly care, cardiology and respiratory care for phase two
 - Communication skills training expertise, including personalised care planning
 - Educational skills, with a focus on workforce development in secondary care
 - Evaluation expertise, including capturing data and insights from patients and secondary care settings.
- **Developing a ‘train the trainers programme’.** The development group would establish a train the trainers team, create a faculty of trainers and simulated patients, and liaise with wider stakeholders at local and national levels.
- **Appointing a national project team** to manage national rollout and implementation of this intervention. The roles of this team would include: supporting and coordinating development group activities and the work of the train the trainers team; developing training materials; procuring and sharing promotional materials; engaging with Trusts to promote participation in the training programme and subsequent delivery of conversations; organising training sessions and liaising with trainers/simulated patients; monitoring training and implementation; liaison with national stakeholders and the governance board; risk and budget management; and oversight of work undertaken to evaluate the intervention.
- **Identifying an appropriate governance body** to oversee the national rollout. We recommend a dedicated project board reporting to NHS England’s End of Life Care Programme Board.

Actions to support monitoring and evaluation

20. Information recorded by clinical staff undertaking care planning conversations at each Trust would need to meet national monitoring and evaluation requirements. As noted above, Trusts would need to submit the relevant data to the national project management and evaluation teams. To facilitate monitoring and evaluation, we recommend exploring options for national standardised planning documents and data as the rollout progresses.

Critical success factors

21. Successful introduction of goals of care conversations for patients approaching end of life is likely to depend on the following critical factors.
 - NHS managers and clinicians embed **a culture of shared decision-making**. Open conversations with patients about their care and wishes at the end of their lives become 'business as usual' as Trust staff recognise these conversations are critical to patients' wellbeing.
 - Clinical staff within all AMUs and SAUs (plus cardiology, respiratory and elderly care units during phase two) undertake goals of care conversations to the **same quality standard** and capture common information fields. This would ensure patients have equal access to high quality goals of care conversations whichever Trust they are admitted to, and enable monitoring and evaluation of the conversations.
 - Trust leaders and AMU/SAU managers **release clinical staff** to participate in the training and **free up capacity** for clinicians to undertake the conversations on an ongoing basis. This is one of the biggest challenges to implementing the intervention, given the multiple competing demands on staff in acute settings. Communication between the national project team and the Trusts involved will be critical.
 - **NHS England & NHS Improvement prioritise** the intervention, management of its development and implementation, and oversight of its evaluation.
22. To realise success, **staff need to understand why** they are being asked to hold the goals of care conversations and *what* it will mean for them and their patients in practical terms. The **benefits must be clearly articulated** – both to and by senior leaders and frontline clinicians – including the anticipated outcomes for patients and the expected implications for service use. Trusts need to disseminate a nationally-designed communication programme to raise awareness, inform staff about training, identify the expected benefits and supporting evidence, share the actual results, and show how the intervention aligns with priorities in the Long Term Plan. Communication about this intervention is likely to need to be continuous, not just during its initial introduction in each Trust.

1. Introduction

Background

- 1.1 Over the past 20 years a wealth of studies has shown the positive effects of interventions to improve communication between clinicians and patients. Studies from around the world demonstrate that effective patient/clinician communication can improve patient experiences and health outcomes.
- 1.2 The positive impacts have been widely evidenced and reported, but there has been no systematic analysis of the case for investing in interventions to improve clinician communication with patients in the NHS. This report sets out that case for investment, presenting the findings from a systematic analysis of interventions studied for evidence regarding their experiential, clinical and financial outcomes.

A Long and Winding Road

- 1.3 *A Long and Winding Road*⁷ by Andrew McDonald was published by Marie Curie in 2016. It set the scene for this study, presenting evidence regarding the impacts associated with effective communication between clinicians and patients. It set out the case that, in addition to experiential and outcome improvements, effective communication is also likely to offer financial efficiencies.
- 1.4 The publication generated some interest in the health and social care community in England and highlighted the need for further research into the case for investment.
- 1.5 In 2017, Sir Simon Stevens commissioned work to develop the ideas outlined in *A Long and Winding Road*. This work was taken forward by the Clinical Communications Steering Group ('the Steering Group'), convened for this purpose, bringing together representatives from NHS England, Health Education England, the Care Quality Commission, the King's Fund, National Voices and Chapter 2 (a group of practitioner and academic experts).
- 1.6 This Steering Group commissioned the systematic evidence review into clinician communication with patients which has informed this report.

Purpose of the review

- 1.7 *A Long and Winding Road* identified the need to improve communication between clinicians and patients in the NHS, making a clear case for the experiential and outcome benefits associated with effective communication. The report also identified priority challenges to be addressed and suggested potential means of doing so.
- 1.8 This review has sought to develop the case further, identifying improvements that have been proved to a sufficient extent (in terms of clinical, experiential and financial outcomes), for a recommendation to be made to NHS England & NHS Improvement for implementation within the NHS in England.

⁷ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/the-long-and-winding-road.pdf>

- 1.9 To achieve these goals, this review therefore needed to identify improvements that have already been developed into a workable intervention and have demonstrated clear outcomes via rigorous trials. The review was designed to ensure that any improvements identified could be:
- Replicated accurately by policy makers, commissioners and service managers across the NHS, using a clear pre-existing action plan already drawn up by researchers.
 - Confidently projected to realise specific experiential, clinical and financial outcomes when replicated accurately within the NHS, based on the intervention having already achieved these outcomes elsewhere.

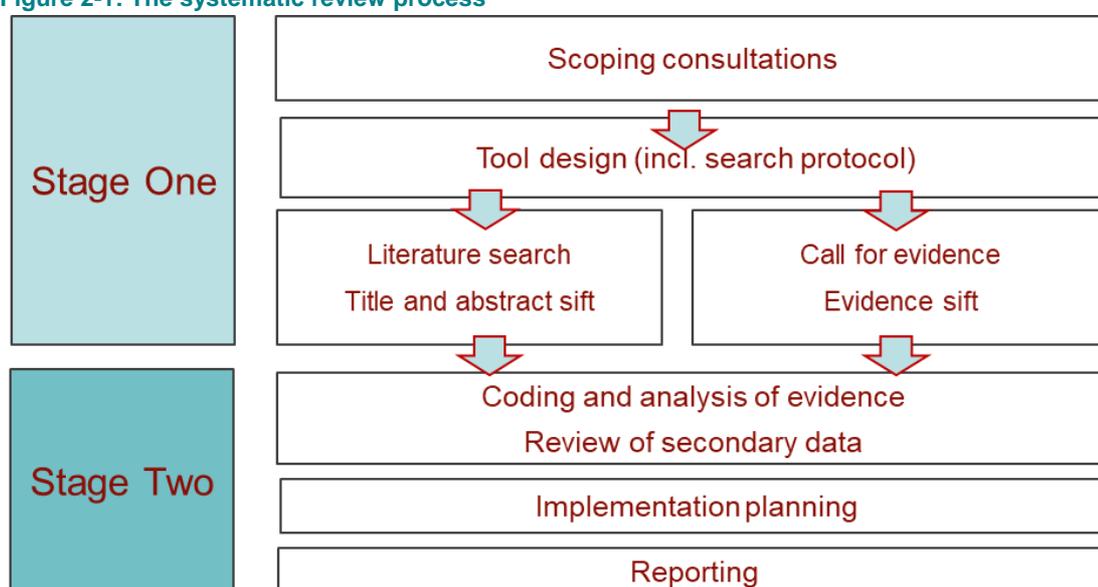
This report

- 1.10 The report has been prepared by [SQW](#), an independent research and consultancy organisation. SQW, with search support from the King's Fund Library Service and strategic oversight provided by the Steering Group, undertook the evidence search and review process.
- 1.11 This report presents the key findings emerging from the international systematic review, outlining the evidence base and the case for change for improving communication between clinicians and patients in the NHS in England. This is illustrated in detail regarding one intervention evidenced as offering clear potential to improve experiential, clinical and financial outcomes; an intervention focused on **goals of care conversations with patients presenting in Acute Medical Units (AMUs) and Surgical Assessment Units (SAUs)**.
- 1.12 The report sets out a compelling case for investment in the intervention. This report will be of interest to policy makers, commissioners and service managers seeking to improve communication between clinicians and patients. It assumes no prior knowledge of the intervention explored or the underpinning evidence base.
- 1.13 This report contains the following chapters:
- **Methods:** a detailed overview of the methods used to undertake this review.
 - **The evidence base:** key findings from the review, including **recommendations for the intervention** with the most significant potential for implementation by NHS England & NHS Improvement.
 - **Conclusions:** key messages from this report and recommendations for policy makers and commissioners.

2. Methods

- 2.1 This chapter sets out the methods used to conduct the systematic review. It details both the process used to search for and identify relevant evidence, and the analytical framework applied during the review of that evidence.
- 2.2 Evidence was collected via two primary channels: a structured search of academic literature databases; and a call for evidence, disseminated to academic and clinical experts in the field of clinician-patient communications.
- 2.3 A flow diagram summarising the review methodology is set out in Figure 2-1

Figure 2-1: The systematic review process



Source: SQW

Establishing parameters for the review

- 2.4 Initial meetings were undertaken to agree the scope, parameters and focus of the review. The SQW research team first met with the Steering Group, to agree the detailed requirements and work-plan.
- 2.5 After this initial meeting consultations were undertaken by SQW researchers with key stakeholders identified by Steering Group members (with 16 individual consultations undertaken in total, informed by a semi-structured topic guide). These stakeholders were identified as being experts and key individuals from academia, the voluntary and community sector and the NHS, each bringing different relevant knowledge and experience of the existing challenges in clinician-patient communication and opportunities for improvement.
- 2.6 Topics explored during these consultations included:
- The scale and nature of the need for change.
 - Past and continuing communication improvement initiatives.

- Existing evidence on the effects of improved clinician-patient communication.

Search protocol

- 2.7 A protocol for the literature search was developed, informed by previous evidence reviews in this field (including *A Long & Winding Road*) and the scoping consultations with stakeholders. The protocol was developed detailing the key research questions of the review and the inclusion/exclusion parameters for documents identified by the search. This included publication dates, region/country of focus, and language of publication. The full protocol is included in Annex A.
- 2.8 The protocol also detailed a set of search terms to be used, covering:
- **Different types of intervention**, including communication techniques and tools that clinicians might use.
 - **Care settings** in which interventions might be applied (including terms relating to specific patient cohorts and clinical staff roles).
 - **Impacts and benefits** likely to be associated with an improvement in communication.
- 2.9 This protocol was then used by the King's Fund Library Service to search eight healthcare-related academic literature databases⁸. This search returned a list of 1,584 documents within scope.

Call for evidence

- 2.10 In addition to the literature search, the search protocol was disseminated to networks of leading academic and clinical experts in the field of patient-clinician communication, identified by the Steering Group. These experts were invited to submit documents that they felt answered the research brief. The parameters for these documents were widened, to include both published and unpublished research and evidence into the effectiveness of local trials or pilot interventions.
- 2.11 The search protocol was disseminated via two primary channels: a call to the membership of the International Association for Communication in Healthcare (EACH)⁹ and a 'snowball' dissemination campaign among NHS staff and providers. In both cases the search protocol was distributed via email, with responses submitted to a central mailbox monitored by the SQW study team. The call remained open for four weeks.
- 2.12 In total, 115 documents were submitted to the review team in response to the call.

⁸ British Nursing Index (BNI); CINAHL (Cumulative Index to Nursing and Allied Health Literature); EMBASE; Health Business Elite; HMIC; The Department of Health Library and Information Services database; The King's Fund Information and Knowledge Services database; PubMed.

⁹ <http://www.each.eu/about-us/>

Title and abstract sift

- 2.13 The literature database search and call for evidence returned a total of 1,699 unique documents. The reference lists of all 1,699 were then searched, identifying an additional 2,488 titles. This produced an initial longlist of 4,187 titles.
- 2.14 These documents were first sifted according to their titles. Each title was reviewed and documents clearly out of scope for this study were excluded. Reasons for excluding documents during the title sift included the document clearly detailing:
- Clinical procedures not including patient-clinician communication (e.g. research on surgical procedures).
 - Sharing of information between clinical practitioners (not the sharing of information between clinicians and their patients).
 - Theoretical or proposed interventions (i.e. not an intervention that had been applied and tested).
 - Implementation of an intervention, without exploring its impacts.
- 2.15 This title sift reduced the list to a total of 344 documents that clearly discussed impacts of communication improvements for patients.
- 2.16 These 344 documents were further sifted through review of the abstracts. Similar to the title sift, the purpose of the abstract sift was to identify the documents that examined existing interventions to improve clinician-patient communication and detailed the impacts of these.
- 2.17 Reasons for excluding documents during the abstract sift included documents examining the take up or use of an intervention, or an intervention's impact on clinicians' knowledge or skills, without considering the knock-on effects on patient care or outcomes. Documents clearly meeting one of the exclusion criteria used during the title sift stage were also excluded¹⁰.
- 2.18 All sifting was undertaken using EPPI-Reviewer software. Each document was uploaded to this software and assigned a code detailing the reasons for its inclusion/exclusion at each stage of the sift. Members of the review team met regularly to audit samples of documents and the inclusion/exclusion decisions made on each, to ensure codes were being applied consistently by all reviewers.

Review process

Development of an initial shortlist of interventions

- 2.19 The abstract and title sift produced a list of 169 documents. Thematic analysis was then undertaken of these 169 documents to identify areas where the evidence base was strongest. This included identifying patient cohorts, types of intervention and care settings for which the

¹⁰ During the title sift documents were excluded only if their titles clearly demonstrated that they did not fall within the scope of this review. If their title was ambiguous, they were kept in for the abstract sift. Some (75) of these documents were then found to be clearly out of scope once their (more detailed) abstract was reviewed.

broadest evidence base existed, as well as a critical review of the methods used to test the intervention examined by each document.

- 2.20 At this stage, studies that had been conducted using a randomised controlled trial (RCT) approach or had been highlighted as priority for review by stakeholders were prioritised. This process identified a shortlist of 84 documents for full review.

Full text review

- 2.21 A full text review was then undertaken of all shortlisted documents. The aims of this review were to identify interventions that:

- **Were well-evidenced.** The review needed to draw on evidenced improvements in patient experience and/or outcomes tested via a rigorous trial.
- **Were replicable.** Studies needed to be reported in sufficient detail to enable the replication of the intervention (i.e. the studies had to include details of the key elements of the intervention and the resources needed to implement it).
- **Could be readily adopted within the NHS.** Alignment between the intervention and current NHS strategic priorities/challenges was explored, to increase the likelihood of securing buy-in from health service leaders, and to minimise the likelihood of any intervention conflicting with ongoing NHS transformation work.

- 2.22 A structured review template was used to extract information from each document reviewed. This template contained a range of different fields, each detailing the specific piece of information required from each document (or the absence of that information noted clearly). Factors explored under each of these topics are described in more detail in the following subsections.

Study design

- 2.23 This section of the review template captured evidence on the methods used by the researchers trialing each intervention. This included examining:

- **Study structure:** including whether the study used an RCT, before-and-after study, cohort study, literature review, or other trial/evaluation approach.
- **Size and makeup of study sample:** the scale at which the intervention had been trialed and the range of factors considered when selecting patients for trial and control groups, and consequently the likelihood of findings being replicable.
- **Study location:** whether the intervention was trialed in one specific locality or multiple localities¹¹, as well as the country in which the intervention was trialed¹².

- 2.24 A brief description of the study was provided including details on the size and profile of the patient sample, and timeframes for delivering the intervention and data collection. The review

¹¹ i.e. the number of different local contexts within which the intervention had been demonstrated to be impactful.

¹² As healthcare systems in other countries differ from the English system to varying degrees.

further considered whether the study used a comparator group, and whether data collected were quantitative and/or qualitative.

Intervention details

- 2.25 Reviewers examined the level of detail the documents provided regarding the interventions examined. This included details of:
- Staff delivering the intervention (including numbers and roles).
 - The patient cohort affected by the intervention.
 - The setting in which the intervention was delivered (e.g. GP surgeries, Intensive Care Units (ICUs)).
 - The precise change made to the way that clinicians and patients were communicating.
 - Resources required to deliver the intervention¹³.
- 2.26 A further consideration was whether the intervention was delivered by healthcare providers' existing workforces or whether new or external staff had supported implementation. The review further highlighted the care setting in which the intervention was implemented (e.g. primary or secondary) and details of the patient cohort targeted, including at what stage in their care they received the intervention and whether specific patients within the cohort were targeted.
- 2.27 The review identified whether documents detailed the costs of implementation, including set-up and implementation costs (such as the cost of producing resources, or any time required from staff to attend training).

Impacts

- 2.28 Reviewers captured detail on a range of potential and actual impacts demonstrated by each intervention. Reviewers examined documents for evidence on a range of impacts including:
- **Improved patient experience:** better patient satisfaction with care they had received and the extent to which they were able to influence decisions about their care.
 - **Improved patient wellbeing:** including decreased anxiety during and after treatment.
 - **Health outcomes:** including any improvement in patients' conditions, or reduction in mortality rates.
 - **Subsequent interaction with/use of healthcare services:** including (for example) whether patients were visiting their GP or A&E less, whether patients were readmitted, or whether patients were opting for less intensive courses of treatment.

¹³ Including physical resources (such as planning documents or digital software) and additional time input required from clinical staff (if, for example, an intervention necessitated increasing the length of a standard appointment).

- **Impacts on staff and service efficiency:** such as shortened appointment times, or time freed up to deliver direct patient care.
- Improvements in staff morale and retention.

2.29 Other impacts such as reductions in complaints or litigation were also considered.

2.30 The robustness of the evidence for each impact was examined. This was done by looking at the data and methods used to calculate impacts, any assumptions made by study authors, and time periods covered. These methods and any limitations to the way impacts were calculated (including any limit on the transferability of findings) were captured.

Alignment with NHS strategic priorities

2.31 Reviewers explored each intervention's alignment with existing NHS strategies¹⁴, policies and challenges (including key population health challenges, such as increasing rates of heart disease and respiratory conditions). The purpose of this was to:

- Ensure that the shortlisted intervention(s) would not conflict with any existing NHS programmes of work.
- Identify interventions that could help the NHS address existing system-based or population health challenges and priorities.

Evidence synthesis

2.32 Findings from the full review of all documents were then collated and synthesised by the research team to identify the interventions for which a sufficiently broad and robust evidence existed to support recommendation to the NHS. Both the findings from this synthesis and the process followed to identify workable interventions are set out in more detail below.

¹⁴ Including the *Five Year Forward View* (the Long Term Plan was not yet published at the time of the document review being conducted, although its priorities and workstreams were reviewed and taken into account during later discussions and planning).

3. Evidence regarding effective communication between clinicians and patients

The nature of the benefits identified

- 3.1 Of the 84 documents reviewed, 35 clearly demonstrated that their interventions delivered improvements. The review identified four interventions that appeared most promising in terms of the impacts identified. These are discussed below.

Decision-making tools for surgery candidates

- 3.2 Several decision-making tools (DMTs) were examined in the documents reviewed. These took the form of brochures and videos given to patients deciding whether to undergo surgery¹⁵. These tools presented risks and benefits associated with two different scenarios: undergoing surgery or forgoing surgery.
- 3.3 Use of these DMTs was evidenced to enhance patient experience of their care, with patients who used DMTs feeling (and demonstrably being) more knowledgeable about their condition and the treatment options available to them, and more confident that they had made the right decisions about their care¹⁶.
- 3.4 Use of shared decision-making tools was found to have significant impacts on reducing instances of surgery¹⁷ and supporting faster discharge of patients from hospital¹⁸. These impacts have been demonstrated without patients' use of other services being observed to increase¹⁹, or any negative impacts on their health or quality of life being observed. The latter point is particularly important, as it indicates that the surgeries avoided are not medically required by patients (who would therefore be undertaking an intensive procedure for limited or no benefit to their health or wellbeing).

Decision-making tools encouraging cancer screening uptake

- 3.5 Evidence from four documents, based on RCTs in England, established that DMTs could be used to increase rates of cancer screening uptake by up to 50%²⁰. These DMTs were also demonstrated to lower patients' decisional conflict²¹ (i.e. patients were more confident that the choice they had made was the best one for them). They also improved patient satisfaction with their care²².

¹⁵ Primarily focused on coronary bypasses, back surgery, and hysterectomies.

¹⁶ Kennedy et al, 2002

¹⁷ Morgan et al, 2000

¹⁸ Phelan et al, 2001; Deyo et al, 2000

¹⁹ Two documents examined patients' subsequent use of specific primary care services or condition-related therapies and found that patients' use of these did not increase (although neither examined an exhaustive list of all services the patients might have accessed following the intervention).

²⁰ Miller et al, 2011; Pignone et al, 2000; Ruffin et al, 2007; Schroy et al, 2012

²¹ Montgomery, 2003.

²² Matthew et al, 2013

Structured conversations with patients about their prescriptions

- 3.6 One document detailed a study in which general practitioners trialed different methods of communicating the risks and benefits associated with the use of statins to patients with high cholesterol²³. Two different approaches were taken:
- *Prolongation of Life (POL)*: patients were informed of their life expectancy if they did not start medication, and the amount of time by which medication could extend that life expectancy.
 - *Absolute Risk Reduction (ARR)*: patients were informed of their risk of dying in the next 10 years, and the impact that taking medication could have in reducing that risk.
- 3.7 This study found that when risks and benefits were presented to patients using the ARR format, a significantly higher proportion took up prescriptions for statins. Patients' satisfaction with their care and confidence in the decision(s) they made were also examined, although no significant impact was observed.
- 3.8 Patients' subsequent adherence to statin treatment once they had redeemed their prescriptions was not examined.

Personalised care planning during end of life

- 3.9 The review identified three interventions for end of life care planning, relating to place of death and goal setting.
- 3.10 One intervention involved nurses discussing preferred place of death with patients as part of a hospice's assessment process, and recording their preferences in a personal care planning document²⁴. This intervention was tested in a retrospective cohort study undertaken in England. This study found that undertaking advance care planning with these patients was associated with a significant increase in patients having their preferred place of death documented by clinical staff. One consequence of this was that patients were more likely to die at home than in hospital. Dying at home is something national attitude surveys indicate more patients would prefer to do²⁵ than currently actually do²⁶, suggesting this intervention helped ensure the care received by patients was better aligned with their wishes than it would otherwise have been. Patients undertaking advance care planning also spent fewer days in hospital during their final year of life.
- 3.11 Another intervention involved registrars and nurses holding personalised goal setting conversations with hospital in-patients referred to an ICU. This before-and-after cohort study, undertaken in Australia, produced evidence of a decrease in medical emergency team²⁷ calls and an increase in patients feeling that care was aligned to their wishes²⁸.

²³ Harmsen et al, 2014.

²⁴ Abel et al, 2013.

²⁵ Park et al, 2013.

²⁶ NHS Information Services, 2010.

²⁷ Also known as a rapid response team (RRT) or high acuity response team (HART).

²⁸ Orford et al, 2017.

- 3.12 The third intervention relating to end of life care planning involved consultants and nurses having briefing and planning discussions with the families of patients admitted to an ICU. This study in the US was able to evidence a lower mortality rate and fewer days spent in ICU and hospital²⁹.
- 3.13 These three interventions were presented (alongside the other shortlisted studies outlined above) to a meeting of the Steering Group, for discussion and review. It was agreed that, based on the evidence presented, suitability for application in the NHS in England, strategic alignment and potential to realise positive outcomes (see criteria below), a blended approach of the three end of life care interventions would be taken forward for development into a costed implementation plan.

Converting the evidence into an action plan

- 3.14 To determine which interventions had the potential to be converted into a workable action plan for the NHS, each was reviewed against specified criteria (listed below). These included the level of detail the documents provided on intervention structure and implementation (collected during the review).
- 3.15 To be confident that an intervention could be replicated accurately by policy makers, commissioners and service managers across the NHS, sufficient detail was required on:
- Staff delivering the intervention (including numbers, roles and any new posts needed).
 - The patient cohort affected by the intervention.
 - The setting in which the intervention was delivered (e.g. GP surgeries, ICUs) and the stage of pathway or journey at which it was implemented (and how long for).
 - The precise change made to the way that clinicians and patients were communicating.
 - Financial resources required to deliver the intervention.
- 3.16 This detail was required to inform an action plan to be drawn up by the review team, suitably clear and detailed that those replicating the intervention could do so in a manner that remained faithful to the original intervention trialed. This was to help ensure that benefits and impacts realised during interventions' previous trials could also be replicated during rollout within the NHS.
- 3.17 It was also important to ensure that any recommended intervention would not duplicate initiatives already underway within the NHS in England. Candidate interventions were therefore discussed with the Steering Group, who provided guidance on ongoing programmes of work being undertaken by NHS England & NHS Improvement and partner organisations (such as Public Health England) that might overlap or clash with interventions identified by the review. Where any conflicts were apparent, an intervention was not developed into a formal recommendation of this review.

²⁹ Ahrens et al, 2003.

Intervention recommended

- 3.18 Following this process, **one intervention was identified as viable: an intervention to improve end of life care planning**, blending elements of interventions examined by three different studies.
- 3.19 The intervention using DMTs to increase cancer screening uptake was not taken forward as it risked overlapping with a cancer screening awareness raising campaign Public Health England were already developing. Similarly, the intervention using DMTs with surgery candidates was not taken forward as we understand a programme of work is already underway within NHS England & NHS Improvement to implement a range of new DMTs, the function of which broadly aligns with that of the DMTs identified by this study. The intervention for increasing take up of statin prescriptions was not taken forward due to concerns about the transferability of its findings to the NHS.
- 3.20 The recommendation regarding goals of care conversations within end of life care is explored in detail below.

Recommended intervention: goals of care conversations in end of life care

This recommendation presents the case for NHS England & NHS Improvement introducing goals of care conversations with patients presenting in Acute Medical Units (AMUs) and Surgical Assessment Units (SAUs) who are at risk of dying in the next 12 months.

These conversations – held within 48 hours of patient admission - involve providing patients with information about their condition and treatment options, and giving them the opportunity to have their values, goals, priorities and treatment preferences heard and respected by clinical staff. These values, priorities and preferences will then be captured in a single care planning document.

This recommendation draws on evidence from the studies and sources listed in this report's bibliography. In particular, it is informed by studies that examined the impact of three personalised end of life care planning interventions which are discussed below. Key elements from each of the three have been blended into one single, cohesive care planning conversation recommendation, the structure and implementation of which have been refined in collaboration an advisory group comprising academic and clinical experts in end of life care and patient-clinician communications. It is this blended approach that offers the most compelling case for replication in the NHS in England.

We recommend an initial proof-of-concept in one Trust, to inform wider roll-out.

Supporting evidence and underpinning rationale

- 3.21 This recommendation draws on evidence from the studies and sources listed in this report's bibliography. In particular, it is informed by three studies that examined the impact of three personalised end of life care planning interventions: Abel et al, 2013; Ahrens et al, 2003; Orford et al, 2017:

- *Abel et al:* Advance care planning conversations were held by hospice and community nurses, with patients in an English hospice.
 - *Ahrens et al:* Personalised goal setting conversations were held with the families of patients (and the patients themselves, if their condition allowed), by a registrar and a clinical nurse specialist. These conversations took place after patients were admitted to an American ICU, and the patients were deemed at high risk of death.
 - *Orford et al:* Patient-centred goals of care discussions were held between medical/nursing staff and hospital in-patients with life-limiting illnesses prior to them being referred to an Australian ICU.
- 3.22 These three interventions each included key elements to ensure personalised care planning conversations were successfully facilitated with end of life patients (and, in one case, their families as well).
- 3.23 A blended intervention has been recommended. This blended approach utilises core elements of each of the three interventions set out above, combined into one single, cohesive care planning conversation and implementation plan. This conversation and implementation plan have both been refined with input and oversight from an advisory group comprising academic and clinical experts in end of life care and patient-clinician communications³⁰.

Rationale

- 3.24 Conversations around prognosis and end of life are challenging for both the clinician and the patient, but are vitally important for improving patient experience.
- 3.25 Currently, attitudes within the medical profession and a culture of targets and pressure within the healthcare system do not always support physicians and other clinicians to prioritise proactive conversations in clinic or on the ward. Experts argue that clinicians have often not been sufficiently trained to feel confident enough to initiate these conversations. However, these discussions are fundamental to effective clinical management plans. Given the increasing proportion of people living with one or more long-term conditions, it is more important than ever that we do not shy away from these conversations.
- 3.26 Evidence shows that there are many potential benefits from the early introduction of end of life care and palliative care planning in a patient's treatment. These approaches can improve quality of life and wellbeing, reduce the use of aggressive care at the end of life, improve clinicians' understanding and delivery of the patient's preferences (including place of death), improve pain management towards the end of life, and reduce emergency hospital admissions. The evidence shows that these conversations not only have the potential to improve patient experiences but also lead to more effective use of resources and generate cost savings to the system as a whole.
- 3.27 Improving communication about the goals of their care can enable people to participate in shared decision-making, and improve the quality of decisions jointly made to guide treatment and care.

³⁰ This is a body convened specifically for the purpose of developing and refining this recommendation. It is separate to the Steering Group that oversaw the review.

Intended beneficiaries of this intervention

- 3.28 People who present to secondary care with an acute episode of ill-health, and are:
- At risk of dying within the next 12 months because of progressive illness or frailty; or
 - At risk of serious clinical deterioration and death during this presentation.
- 3.29 During the first phase of this project, the group targeted for this educational intervention would be frontline doctors, nurses and allied health professionals working in all **Acute Medical and Surgical Assessment Units across England**.
- 3.30 During the second phase, this would be extended to the **respiratory, cardiology and elderly care wards** across England.

Intervention

- 3.31 This section details the key elements of the intervention we are proposing NHS England & NHS Improvement implement. As stated above, this is based on a blended review of the three interventions identified within the documents reviewed; each of those individual interventions did not necessarily involve each element outlined below.
- **Care planning conversations take place in AMUs and SAUs** with all admitted patients who are identified as being at increased risk of serious clinical deterioration and death during their presentation³¹ and/or at risk of dying within the next 12 months³².
 - **A frontline clinical member of staff holds a conversation with each patient.** This trained staff member – a core medical trainee (CT2), specialist registrar (ST2), charge nurse, advanced nurse practitioner or band 6-7 physiotherapist or occupational therapist - provides medical updates, guidelines for care, and explains the care options available to the patient (including and in addition to curative care), then discusses the patient's values, treatment options and preferences with the patient and/or their family (depending on who is available and able to participate – ideally both).
 - The staff member uses a planning document to capture the patient's values, priorities and treatment/care preferences. This is a live document, created during the first conversation and updated (if necessary) during subsequent conversations. Patients and their families keep a paper version for their own ongoing use/reference. Staff also record key outcomes and decisions made in their organisation's electronic system.

³¹ Using the National Early Warning Score (NEWS) 2 screening tool.

³² Using their frailty score, the Supportive & Palliative Care Indicators Tool (SPICT) and the Gold Standards Framework (GSF).

Implementation plan

Project set up, development group formation and faculty development

- 3.32 One of the three documents cited above (Orford et al, 2017) demonstrated the necessity for staff training and detailed the training required to enable delivery of the intervention. By adapting the content of this course (iValidate³³) for an NHS context, the advisory group supporting this review has advocated developing a training programme that should be attended by AMU/SAU staff who would be responsible for holding goals of care conversations.
- 3.33 It will be vital to **establish a ‘development group’** with appropriate skills and expertise to design the training programme in detail. The specific skills and inputs needed include:
- Clinical expertise and knowledge regarding end of life care and AMUs/SAUs.
 - Communication skills training expertise, including engagement with vulnerable people and personalised care planning.
 - Educational skills, with a focus on workforce development in secondary care.
 - Evaluation expertise, including capturing data and insights from patients and secondary care settings.
- 3.34 The development group has a key role in designing this training for Trusts. It will also oversee the creation of a **faculty of trainers and simulated patients**. Developing this faculty would likely involve a number of key steps, including:
- Developing a ‘train the trainers’ programme
 - identifying and recruiting a small, high quality group of relevant experts with the necessary time and enthusiasm to design, develop and deliver the train the trainers programme, through which the trainers who will deliver the training and briefings in Trusts will be trained.
 - Recruiting to and developing a faculty of trainers with the capacity and skills needed to deliver the training programme to the Trusts
 - recruiting sufficient numbers of trainers capable of delivering communication training to clinicians in the Trusts
 - establishing a system for accrediting trained trainers, with annual/bi-annual updates of the accreditation.
 - Recruiting to, developing and training a faculty of simulated patients, specifically trained in this aims, objectives and simulated patient roles for this programme
 - simulated patients will need sufficient capacity and relevant experience to enable them to role-play during training delivered to Trusts and be trained to improvise appropriately and provide effective constructive feedback.

³³ More information on the iValidate education programme can be found [here](#).

- Overseeing a proof of concept of the two-day modular Trust training programme.
 - Developing a community of practice of the trainers who will deliver the training to Trusts. We recommend that a virtual community of practice be formed, to enable trainers to engage directly with one another after attending the ‘train the trainers’ session(s). This is likely to offer benefits to trainers by way of peer support. A Google Group or WhatsApp group might work well for this function.
 - Supporting initial communications and engagement with local and national stakeholders, which we anticipate would subsequently be led by the project director longer term once they become established in the role. This will involve informing the design of a brochure and communication materials for use with local leaders and clinical leads in order to gain buy-in, including setting out the intervention’s purpose and expected benefits, including financial returns expected for Trusts and the time commitment required
 - it is anticipated that interested parties to be targeted with communication and awareness raising materials regarding the project will include, as a minimum, all Trust medical education departments, Sustainability and Transformation Partnerships / Integrated Care Systems and Strategic Clinical Networks at local and regional levels, as well as Health Education England and relevant Royal Colleges at a national level.
- 3.35 Finally, there is likely to be an ongoing role for the development group in providing expert advice and critical challenge throughout the project.

Proof-of-concept work

- 3.36 This report proposes that initial proof-of-concept work is then undertaken to test this intervention in a real-world setting. This work has been anticipated to commence and be completed during the 2020/21 financial year, following establishment of the development group and recruitment/training of an initial training faculty.
- 3.37 This proof-of-concept work would serve two purposes:
- **Producing learning on best practice in implementation**, identifying the practical challenges associated with implementing this intervention in a secondary care setting and learning to ensure implementation is as efficient and effective as possible.
 - **Generate evidence of the ‘true’ impacts of the intervention**, exploring both the experiential and clinical benefits realised for patients as well as examining the knock-on implications for the Trust, clinicians and other health and social care providers in their area.
- 3.38 NHS England & NHS Improvement should first identify a Trust willing to act as a ‘demonstrator’, implementing goals of care conversations locally to generate the proof-of-concept.
- 3.39 NHS England & NHS Improvement would then closely monitor and evaluate progress and outcomes/impacts of proof-of-concept work at the demonstrator Trust. This evaluation

would produce evidence that the approach set out in this report works in a present-day NHS context (evidence that could then be used to help secure buy-in from other Trusts during subsequent years), as well as learning on the practical steps that need taking to make this intervention operational and deliverable within a secondary care setting.

- 3.40 Alongside this, work should be undertaken with stakeholders to more precisely model the implications of patients who receive the intervention spending fewer days in hospital, include the full impacts on Trust service utilisation, cost bases and income. This modelling would feed into both evaluation of the proof-of-concept work and evaluation throughout the subsequent national rollout.
- 3.41 A reasonable process might involve six months of delivery of conversations, with a further 12 months allowed for all patients involved in the trial to fully realise the anticipated benefits from their receipt of the intervention. Assuming a start date of October 2020, the six-month delivery period could therefore potentially be completed by the end of March 2021.

Staff training

- 3.42 Staff undertaking the goals of care conversations would need training to identify patient values, to listen to patient preferences, and to provide advice to high-risk patients accessing acute care. The content of the course would need to be agreed and developed by the 'train the trainers' team. Based on the evidence from the published studies and advisory group inputs, anticipated core content of this **training course**³⁴ include:

- Learner-centred approaches exploring participants' prior knowledge, confidence and needs in undertaking personalised care goal discussions with patients approaching end of life.
- Frameworks both for values-driven end of life care conversations and for effective clinical communication (including the Calgary-Cambridge guide and Harvard Serious Illness guide).
- Guidance on identifying patients at risk of dying over the subsequent twelve months, including use of individual frailty scores, the Supportive & Palliative Care Indicators Tool and the Gold Standards Framework.
- Establishing whether a patient has had a goals of care conversation, during routine patient care handovers.
- Ensuring the timeliness of goals of care conversations, and how to create opportunities to initiate the conversation using appropriate communication skills.
- Key underlying patient-centered communication skills of gathering information about goals, fears and worries, critical abilities, trade-offs, and family circumstances and wishes. These would include agenda setting, assessing illness understanding, rapport building, signposting, listening, reflective questioning, silence, and empathy.

³⁴ The content designed and the facilitators trained by the train the trainers team, via the process detailed earlier in this recommendation.

- Looking for and responding to cues from the patient (and family/carers as appropriate).
 - Presenting and discussing options with the patient and developing consensus (utilising explanation and planning communication skills including patient restatement, exploring patient preferences, shared decision-making).
 - Concluding, summarising and documenting about goals of care agreed³⁵.
- 3.43 Staff would also need sufficient training in **end of life care**, including the different curative and palliative care options available to patients.
- 3.44 Training on the principles and processes of undertaking personalised care planning would need to be given to the clinical staff that would have these conversations with patients about their preferences. One of the studies in this review³⁶ included a 2-day training workshop to prepare staff to deliver personalised care planning, and this aligns with the broader evidence regarding the efficacy of communication skills training. This review's advisory group has recommended that this approach be replicated within the NHS in England. The advisory group recommended that the training programme could be delivered in a modular form, with the modules comprising two days to complete in total. This would be followed by a half-day refresher training session several months later.
- 3.45 Consultants on AMU/SAU rotas would need an introductory session to understand the need for this intervention and how to listen to and act on the information other staff gather through goals of care conversations. Based on advice from this study's advisory group, this session could likely be delivered in two hours.

Delivery of conversations

- 3.46 The studies in this literature review examined different approaches to delivering care planning conversations. Two studies involved conversations initiated and run by one member of staff and produced a care plan or document on patient goals as part of the intervention. This has informed our recommendation that the training could therefore be targeted at key AMU/SAU staff chosen to undertake these care planning conversations with patients: CT2s, ST2s, charge nurses, advanced nurse practitioners and band 6-7 physiotherapists and occupational therapists.
- 3.47 The benchmark used in one study³⁷ was that documentation of a patient's goals needed to take place within 48 hours of that patient's referral to the ICU. This matches the National Quality Forum's quality benchmarks on the speed with which patients admitted to ICU should have their care preferences documented; this benchmark is set at 48 hours, to avoid patients receiving invasive or aggressive care they might not want³⁸. In line with this, we therefore recommend that the **goals of care conversations take place and are documented within 48 hours of patients presenting at AMUs/SAUs.**

³⁵ These topics are identified either in the Orford et al study and/or on the advice of this study's advisory group.

³⁶ Orford et al, 2017.

³⁷ Orford et al, 2017.

³⁸ NQF measure #1626 (further information available [here](#)).

- 3.48 The studies do not state whether the new planning process increased the average length of consultations between staff and patients. The recommendation of this review's advisory group is that an initial conversation to produce the plan could potentially be completed in 30 minutes, and would need to be additional to routine consultations. The plan should then be revisited again prior to the patient's discharge from the AMU/SAU, to ensure any change in their priorities/preferences during their stay is captured in an updated plan. This would mean **two consultations (on top of business as usual activity), each of up to 30 minutes.**

Data capture

- 3.49 The studies examined by this review were applied at a relatively small-scale and were each therefore able to make use of a standardised planning document. This intervention, however, is intended to be rolled out nationally (following an initial proof of concept) and therefore (at least initially) needs to comply with the care planning processes and documentation already in place at each individual Trust.
- 3.50 Information recorded by clinical staff undertaking care planning conversations at each Trust would need to capture a record of patient, values, priorities and treatment preferences, to inform future treatment; and generate sufficient data to meet national monitoring and evaluation requirements. To ensure sufficient information is captured to meet both of these purposes, we suggest that trainers work with staff at each Trust they deliver training to, to ensure that their existing processes and documentation are fit for purpose and to identify any changes/additions necessary.
- 3.51 Trainers would, in advance of delivering their first training session to staff from any one AMU or SAU, spend time familiarising themselves with the care planning document(s) and record keeping systems in use within that unit. If a unit's existing care planning documents and/or record-keeping systems do not capture information needed to meet both the purposes set out above³⁹, trainers would log this with the national project management team, who would liaise with key individuals at each Trust to ensure any necessary data fields are added. The necessary changes could then also be raised and discussed during briefings with senior staff and training sessions with staff who will be undertaking conversations with patients. We have suggested 0.25 days of a trainer's time to review each unit's existing processes and documents⁴⁰.
- 3.52 For monitoring and evaluation purposes, all relevant data would need to be submitted to the national project management and evaluation teams. Collation, standardisation and submission of this data would need to be undertaken by a member of administrative staff located at each Trust. We are proposing that this would require 0.25 FTE input from an administrative staff member at each Trust.
- 3.53 While Trusts' existing planning documents and record keeping systems should all be capable of capturing the level and detail of information required for both care planning and

³⁹ Such information including evidence of a patient's values, treatment preferences (such as preferred place of death) or core clinical outcomes (e.g. length of stay in hospital, incidence of re-admission).

⁴⁰ In our costings we have assumed any costs of data capture and entry to Trusts' record-keeping systems would already be met by Trusts prior to this intervention and that Trusts would therefore continue to cover these.

monitoring/evaluation purposes, we would recommend that options for national standardisation of planning documents and data are explored as implementation progresses.

Project governance

3.54 Dedicated governance would be needed to oversee national rollout of this intervention, including monitoring both rollout and delivery of training, and the implementation of goals of care conversations with patients. The most appropriate body for overseeing this work would be a dedicated project board reporting in to the existing End of Life Care Programme Board⁴¹.

3.55 A **project director, manager and support team** would also be needed, to manage centrally and perform the various tasks associated with the national rollout and implementation of this intervention. Given the activities and processes set out above, the roles of this project team are expected to include:

- Supporting and coordinating activities and work of the development group and ‘train the trainers’ team
- Development of training materials
- Procuring and sharing promotional materials
- Engaging with Trusts to promote participation in the training programme and subsequent delivery of conversations
- Booking training sessions and liaising with trainers/simulated patients
- Monitoring delivery/attendance of training, and the subsequent holding of goals of care conversations and documenting of goals
- Liaison with other national stakeholders
- Risk management and monitoring
- Monitoring expenditure against budget
- Reporting progress to a governance board, and oversight of work undertaken to evaluate the intervention.

Benefits and outcomes expected

3.56 Evidence from the studies detailed earlier suggests that this approach to care planning better **ensures patients’ wishes are recorded and adhered to** by staff providing their care^{42,43,44}. Patients who undertake personalised care planning are more likely to receive palliative care instead of curative care. They are also **more likely to die at home than in hospital**⁴⁵,

⁴¹ <http://endoflifecareambitions.org.uk/programme-board-papers/>

⁴² Hammes et al, 1998.

⁴³ Silveira et al, 2010.

⁴⁴ Mack et al, 2010.

⁴⁵ Abel et al, 2013.

something national attitude surveys suggest more patients would prefer to do⁴⁶ than currently actually do⁴⁷.

Better experience for patients and their families

- 3.57 There is strong evidence that advance care planning and a subsequent earlier transition to palliative care can **improve patients' satisfaction with the care** they receive^{48,49}. An earlier transition to palliative care has also been demonstrated to improve family satisfaction and lead to reduced stress, anxiety and depression in surviving relatives⁵⁰. Some studies suggest that advance care planning can **improve patients' quality of life** and spiritual wellbeing⁵¹, and **relieve depression and anxiety**⁵².

Improved outcomes

- 3.58 Various studies have demonstrated that **care planning conversations can help decrease patient mortality rates**, including among nursing home residents⁵³ and patients referred to an ICU⁵⁴. One study found that the survival rates of patients with lung cancer improved when early palliative care was provided instead of standard curative care⁵⁵ - an important finding, given the evidence that patients who undertake personalised care planning are more likely to switch to palliative care instead of curative care.
- 3.59 There is strong evidence that this reduces the amount of time patients spend in critical care. When clinicians hold care planning conversations with patients who have life-limiting/terminal illnesses, **the amount of time those patients spend in hospital decreases**. There is also indicative evidence that care planning of this nature can reduce the rate of patients being admitted to hospital as an emergency^{56,57} or, for patients already being supported in a hospital, requiring a medical emergency team callout⁵⁸.
- 3.60 End of life discussions have also been associated with reduced use of invasive medical care (such as ventilation and resuscitation) and improved quality of life near death⁵⁹.
- 3.61 We anticipate that the evidenced benefits detailed above would be largely transferable to the goals of care conversations we are proposing, given that goals of care conversations share many of the same principles and objectives as other personalised and advance care planning interventions.

⁴⁶ Park et al, 2013.

⁴⁷ NHS Information Services, 2010.

⁴⁸ Gade et al, 2008.

⁴⁹ Detering, et al, 2010.

⁵⁰ *Ibid* 36.

⁵¹ Rabow et al, 2004.

⁵² Molloy et al, 2000.

⁵³ Caplan et al, 2006.

⁵⁴ Orford et al, 2017.

⁵⁵ Temel et al, 2010.

⁵⁶ Ziegler et al, 2018.

⁵⁷ Brumley et al, 2007.

⁵⁸ Orford et al, 2017..

⁵⁹ Wright et al, 2008.

Cost of implementation

3.62 The likely costs of training staff across England to hold planning conversations in this way are set out in Table 3-1: Estimated costs and savings associated with phased rollou below. These have been costed based on the assumptions that:

- All consultants and matrons on AMU/SAU rotas attend a single 2-hour introductory session.
- All AMU/SAU staff who would need to conduct these conversations⁶⁰ attend a 2-day training course, plus a follow up half-day session 3-6 months later, and that backfill is not provided to cover their roles while they attend training.
- Each session is delivered to a group of 8 clinicians⁶¹.
- Approximately 24% of all patients admitted to AMUs/SAUs will be eligible for this intervention⁶². Approximately 43.6% of these eligible patients will experience an impact of a reduction in bed days over the subsequent 12 months⁶³.
- An extra 30 minutes of clinical time is required per patient to hold each planning conversation⁶⁴, with two goals of care planning conversations required on average per patient; these would be absorbed into existing staff workloads and not require a financial outlay.

3.63 A full list of data sources and assumptions is included in Annex C.

Costs and benefits of rollout

3.64 Our analysis shows that rolling this out would free up resources elsewhere in the system, as realising patients' wishes would enable more to leave hospital more quickly (or to avoid it altogether) during the final twelve months of their life. The conservative estimate produced by our modelling⁶⁵ forecasts £509million (2019/20 value) of hospital bed days per year being freed up as a consequence⁶⁶. Taking into account annual implementation costs of £6million (2019/20 value) **this intervention could therefore generate savings of £502million per year and be implemented on an 'invest to save' basis.**

⁶⁰ CT2s, ST2s, charge nurses, advanced nurse practitioners and band 6-7 physiotherapists and occupational therapists.

⁶¹ The optimum group size recommended by the advisory group in order for participants to realise all benefits of the training.

⁶² Based on findings from previous screening programmes used the Gold Standards Framework, reported in Milnes et al, 2015. *A prospective observational study of prevalence and outcomes of patients with Gold Standard Framework criteria in a tertiary regional Australian hospital.*

⁶³ Based on Milnes et al's 2015 study, which screened acute inpatients in an Australian hospital using GSF and found 50.3% of patients who met GSF criteria died within one year of screening. Adjusting this figure for optimism bias, we have estimated this will translate into 43.6% of AMU and SAU inpatients being in their last year of life. (application of optimism bias detailed in Annex C).

⁶⁴ Based on this report authors' experience evaluating personalised care planning pilots.

⁶⁵ Assuming a minimal reduction in hospital bed days.

⁶⁶ Once this intervention has been fully rolled out nationally and a year's lead-in time allowed for impacts to be fully realised. These savings would be offset slightly by the costs of setting up and implementing the intervention, set out in Table 3-1, although the intervention would still realise an overall saving.

Costs and benefits of phased implementation

- 3.65 This section presents the estimated annual costs and savings associated with phased rollout of this intervention nationally (to all relevant Trusts in England). A phased rollout is proposed in acknowledgement of the large number of Trusts and clinicians to be trained to implement the intervention. To accommodate the proof-of-concept work proposed earlier in this chapter, we propose this phased rollout commences in the 2021/22 financial year.
- 3.66 The phasing assumes funding is available to support initial design and proof-of-concept work during year 1 (assumed to be 2020/21), followed by funding for implementation in:
- 25% of English Trusts in 2021/22
 - 50% of Trusts in 2022/23
 - 75% of Trusts in year 2023/24
 - 100% of Trusts in year 2024/25
 - ‘Steady state’ 100% implementation from 2025/26 onwards.
- 3.67 All estimates of costs and cost reductions arising from phased rollout are based on 2019/20 costs, inflated at a rate of 2.1% per year for each subsequent year. The phasing assumes that in any given year, most costs and cost reductions are accrued at a rate proportionate to the extent to which the intervention has been rolled out⁶⁷. National monitoring and evaluation is assumed to be a flat fixed-rate cost in each year of rollout. The full potential annual saving (£502million in 2019/20 values) is first realised 2025/26.

Table 3-1: Estimated costs and savings associated with phased rollout⁶⁸

| | 2020/21 ⁶⁹ | 2021/22 | 2022/23 | 2023/24 | 2024/25 | 2025/26 |
|---|-----------------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Faculty development ⁷⁰ | £86,743 | £7,201 | £14,691 | £22,477 | £30,569 | £31,180 |
| Project management ⁷¹ | £154,308 | £192,920 | £393,557 | £602,142 | £818,913 | £835,291 |
| National monitoring and evaluation ⁷² | £35,000 | £104,040 | £106,121 | £108,243 | £110,408 | - |
| Total central costs | £276,051 | £304,161 | £514,369 | £732,862 | £959,890 | £866,471 |
| Cost of providing briefings and training sessions | - | £1,013,090 | £2,066,703 | £3,162,055 | £4,300,395 | £4,386,403 |
| Input from Trust staff ⁷³ | - | £561,141 | £1,144,727 | £1,751,433 | £2,381,949 | £2,429,588 |

⁶⁷ For example, if the intervention is rolled out to 25% of English Trusts then the national project management costs incurred are 25% of the project management costs we have estimated would be incurred for an intervention implemented in all English Trusts.

⁶⁸ All figures presented have been rounded to the nearest whole integer.

⁶⁹ 2025/26 costs and savings repeated in each subsequent year of delivery. All costs and savings have been adjusted from 2019/20 prices to allow for 2.1% annual inflation (the rate of inflation at the time of writing in 2019).

⁷⁰ Including design of the training programme and faculty development, plus ongoing support of trainers.

⁷¹ Including time for ongoing expert advisory support, communications and awareness raising.

⁷² Including evaluators to undertake scoping work in 2020/21. Assumes evaluation costs stop after implementation reaches steady state.

⁷³ Assumes, at each Trust, a 0.2 FTE Band 8a clinical champion to support intervention rollout and 0.25 Band 4 administrator to collate/ report monitoring data.

| | 2020/21 ⁶⁹ | 2021/22 | 2022/23 | 2023/24 | 2024/25 | 2025/26 |
|---|-----------------------|-------------------|-------------------|-------------------|-------------------|-------------------|
| Total Trust costs⁷⁴ | - | £1,574,231 | £3,211,430 | £4,913,488 | £6,682,344 | £6,815,991 |
| Cost reduction arising from reduced hospital bed days ⁷⁵ | - | £71,674,532 | £211,001,001 | £358,944,150 | £515,948,070 | £572,919,275 |

Source: SQW analysis

- 3.68 Per Trust in England this equates to an average estimated total cost over the 5 years of phased rollout⁷⁶ of £174,837, generating an average total estimated cost reduction over 5 years of £11,384,783⁷⁷.

Proof-of-concept work

Delivering a 6-month proof-of-concept intervention in 2020/21 is estimated to cost £23,510 in an average Trust (assuming the Trust-level and national implementation costs set out in Table 3-1 are incurred)⁷⁸, plus evaluation costs⁷⁹. This is estimated to deliver an average Trust a total cost reduction of £1.7million, due to 713 patients spending less time in hospital within 12 months of receiving the intervention⁸⁰.

These costs and cost reductions of delivering a proof-of-concept intervention have not been included in Table 3-1.

- 3.69 In addition to the assumptions used to calculate the recurrent annual costs and benefits associated with full national rollout of this intervention⁸¹, the phasing of the costs and timeframes within which savings are realised have been determined based on the following additional assumptions:

- All training delivered in a year is delivered in month 6 of that year⁸² (taking a midpoint in the year accepting some will occur later and some earlier).

⁷⁴ Based on English trust

⁷⁵ The cost reduction nominal cost of the bed days avoided due to patients spending less time in hospital. This figure is different from the 'savings' presented in Paragraph 3.68, which are the total savings realised by the NHS once cost reductions realised due to patients spending less time in hospital are offset against the cost of implementation.

⁷⁶ 2021/22 to 2025/26 inclusive.

⁷⁷ Total implementation costs and cost reductions over the five-year phased rollout period of £26,575,237 and £1,730,487,028 respectively, each divided by 152 (the total number of Trusts in England). Costs include those incurred centrally as well as those incurred by individual Trusts.

⁷⁸ Total estimated national implementation costs (minus faculty development) over 2020/21 would be £7,146,986 if the intervention was 100% rolled out during this year. That figure of £7,146,986 has been divided by 152 (the total number of Trusts in England) to produce an estimated cost of rollout in one Trust, and then again by two to reach a six-month figure. Faculty development is not included as this study's advisory group have offered to provide faculty development free of charge for a single demonstrator site.

⁷⁹ A one-off evaluation exploring both the implementation and impact of a proof-of-concept intervention might cost approximately £35-50,000, depending on the specification.

⁸⁰ Total national cost reductions over 2020/21 would be £518,910,639, realised from 216,738 patients impacted by the intervention. This has been divided by 152 (the total number of Trusts in England) and then again by two (to reach a figure of cost reductions arising from the intervention being implemented for a six-month period during the proof of concept phase).

⁸¹ Set out in full in Annex C.

⁸² We assume delivery of training at different Trusts will be staggered throughout each year (given the limited number of trainers available to deliver training sessions). We have produced our calculations on an assumption of all training being delivered in month 6 as this is the likely average point in time at which Trusts will receive their training in any given year.

- Staff members' planning conversations with patients begin immediately following their completion of the 2-day training programme.
- The full cost-saving impact (a reduction in bed days) for each individual patient would be observed within a one-year period following that patient receiving the intervention.
- Training is repeated annually, to ensure the skills and knowledge in each unit are not depleted by staff rotation, secondment or turnover.
- Recruitment and briefing/training of trainers and simulated patients also continues to take place annually, at half the scale undertaken in year 1 (2021/22)⁸³. This would ensure the faculty of trainers and simulated patients is not depleted by turnover.

3.70 It is important to note that no studies examined whether the reductions in patients' use of secondary care resulted in increased use of social, hospice, community or primary care (which would have financial implications for these services). Any additional demand on these and other services due to patients spending less time in hospital could not be accounted for in our analysis. However, the costs and benefits set out above would translate to a net annual saving to the NHS of £2,318 per patient⁸⁴ (2019/20 value), which is likely to offset a modest rise in utilisation of other services⁸⁵. Reducing patient bed days during end of life may also help acute services free up capacity to deal with other pressures, potentially increasing throughput on elective operations and/or improving waiting time performance.

3.71 Knock-on impacts on demands and costs elsewhere in the health and social care system would need to be captured and monitored as part of ongoing review of the intervention's impact.

Wider rollout – phase two

3.72 Our analysis shows that the impact of rolling this initiative out would free up resources, as realising patients' wishes would enable more to leave hospital more quickly (or to avoid secondary care altogether) when at risk of dying within the next twelve months. The estimate produced by our modelling⁸⁶ forecasts £69million of hospital bed days per year (2019/20 values) being freed up as a consequence (generating a net annual saving of £59million). **This intervention could therefore be implemented on an 'invest to save' basis.** A full list of data sources and assumptions is included in Annex C.

3.73 Once implementation within AMUs and SAUs has been completed and goals of care conversations in these settings have become routine, and subject to positive evaluation findings, this study's advisory group has recommended that the approach could be extended to respiratory, cardiology and elderly care wards within acute providers ('phase 2').

⁸³ A cohort of trainers and patients sufficient for delivering full national rollout would be recruited during year one, so recruitment/training activity from year two onwards would only be needed to offset any turnover. It may be that this cost could be reduced if attrition is lower than anticipated.

⁸⁴ When the net saving is divided by the number of patients who experience the reduction in bed days.

⁸⁵ If demand on other services were to increase, consideration should be given as to how the scale of this impact could be determined and sufficient funding reallocated to support the services experiencing an increase in demand.

⁸⁶ Assuming a minimal reduction in hospital bed days.

3.74 The likely additional costs of training staff in these wards, across England, to hold planning conversations in this way are set out in the table below. These have been costed based on the assumptions that:

- All ward staff who would need to conduct these conversations⁸⁷ attend a 2-day training course, plus a follow up half-day session 3-6 months later, and that backfill is not required to cover their roles while they attend training.
- Each session is delivered to a group of 8 clinicians⁸⁸.
- All consultants on these wards' rotas attend a single 2-hour introductory session, and that backfill is not required to cover their roles while they attend the session.
- Approximately 24% of all patients admitted to these wards will be eligible for this intervention⁸⁹, and approximately 70% of those eligible patients admitted to these specialist acute wards will have been admitted via an AMU or SAU⁹⁰, and should therefore have already had goals of care conversations. The additional impacts realised by expanding these conversations to specialist acute wards will therefore be realised by 43.6% of patients who have been admitted to these wards via channels other than AMUs or SAUs.
- An extra 30 minutes of clinical time is required per patient to hold each planning conversation, with two goals of care planning conversations required on average per patient⁹¹; these would be absorbed into existing workloads and therefore not require an additional financial outlay.

Table 3-2: Estimated annual national costs of phase two rollout (2025/26 onwards, excluding ongoing phase one costs)

| | 2025/26 | 2026/27 ⁹² | 2027/28 | 2028/29 |
|---|--------------------|-----------------------|--------------------|--------------------|
| Faculty development ⁹³ | £46,771 | £47,706 | £48,660 | £49,634 |
| Project management ⁹⁴ | £1,348,067 | £1,375,028 | £1,402,528 | £1,430,579 |
| Monitoring and evaluation ⁹⁵ | £3,097,773 | £3,159,728 | £3,222,923 | £3,287,381 |
| Cost of providing briefings and training sessions | £6,804,273 | £6,940,359 | £7,079,166 | £7,220,749 |
| Total implementation cost⁹⁶ | £11,296,884 | £11,522,821 | £11,753,277 | £11,988,343 |

⁸⁷ CT2s, ST3s, charge nurses, band 6 and above condition-specific specialist nurses, and band 6-7 physiotherapists and occupational therapists.

⁸⁸ The optimum group size recommended by the advisory group in order for participants to realise all benefits of the training.

⁸⁹ Based on findings from previous screening programmes used the Gold Standards Framework with acute inpatients, reported in Milnes et al, 2015. *A prospective observational study of prevalence and outcomes of patients with Gold Standard Framework criteria in a tertiary regional Australian hospital.*

⁹⁰ Based on estimate provided by the advisory group.

⁹¹ Based on this report authors' experience evaluating personalised care planning pilots.

⁹² 2026/27 costs and savings repeated in each subsequent year of delivery. All costs and savings have been baselined at 2019/20 prices then adjusted to allow for 2.1% annual inflation (the rate of inflation at the time of writing).

⁹³ Including design of the training programme and faculty development, plus ongoing support of trainers.

⁹⁴ Including time for ongoing expert advisory support, communications and awareness raising.

⁹⁵ Including time for administrative staff at Trusts to collate and compile data submissions, and for evaluators to undertake analysis/reporting.

⁹⁶ All figures presented have been rounded to the nearest whole integer.

| | 2025/26 | 2026/27 ⁹² | 2027/28 | 2028/29 |
|--|-------------|-----------------------|-------------|-------------|
| Cost reduction through fewer hospital bed days ⁹⁷ | £42,183,543 | £79,434,856 | £81,023,553 | £82,644,025 |

Source: SQW

- 3.75 These costings assume that training programme design and development would not need to be repeated for this second phase of rollout, but that additional trainers and simulated patients would need recruiting to deliver the training sessions required.
- 3.76 It is important to restate that no studies examined whether the reductions in patients' use of secondary care resulted in increased use of social, hospice, community or primary care (which would have financial implications for these services). Any additional costs borne by wider health and social care services could therefore not be accounted for in our analysis, but would need to be factored into monitoring and evaluation plans.
- 3.77 The costs and benefits set out above for phase two translate to a net annual saving to the NHS of £2,007 per patient⁹⁸ (2019/20 values). This would mean that, should the level of costs borne by other services rise by less than £2,007, phase two would still produce an overall saving to the health and social care system⁹⁹.

Risk management strategy

- 3.78 Annex D (the Project Initiation Document) presents an overview of anticipated potential risks and issues, alongside proposed mitigation strategies. This has been developed based on the studies identified in the evidence review, as well as our knowledge of other personalised care planning interventions.
- 3.79 One of the most significant risks concerns the engagement and buy-in of Trusts to the intervention and training requirements. This is vital to successful rollout and implementation of the intervention, and this paper has been developed on the assumption that Trusts will act as rational economic actors. Mitigation strategies recommended regarding this centre on:
- Wide-ranging communication activities and engagement with all 152 Trusts, to secure clinical and leadership buy in, and overcome any concerns raised.
 - Emphasising the benefits expected (for Trusts, as well as patients), including the financial case underpinning the recommended intervention.
 - Highlighting how the approach aligns with the requirements set out in the Long Term Plan.
- 3.80 Other risks identified centre around:

⁹⁷ The nominal cost of the bed days avoided due to patients spending less time in hospital. This figure is different from the 'savings' presented in Paragraph 3.74, which are the total savings realised by the NHS once cost reductions realised due to patients spending less time in hospital are offset against the cost of implementation.

⁹⁸ When the overall net saving is divided by the number of patients who experience the reduction in bed days.

⁹⁹ If demand on other services were to increase, consideration should be given as to how the scale of this impact could be determined and sufficient funding reallocated to support the services experiencing an increase in demand.

- Trust and clinician willingness and capacity to commit fully to the training requirements.
- Inconsistent or partial implementation of the conversations and care planning processes, and capacity to undertake the conversations.
- Turnover amongst the trained workforce; reliance on locums who may or may not have been trained and be familiar with Trust-specific care planning documentation.
- Variations in the quality and coverage of Trust care planning documents, risking variable recording and inconsistent (quality of) implementation.
- Patient and family/carer buy in and capacity to engage in a meaningful way.
- Family or carer resistance or concern regarding the decisions or approach taken.
- Patient needs changing, and/or capacity pressures/eligibility thresholds in the system limiting the extent to which patient goals can be realised.
- Conversations not being undertaken to the extent anticipated, and/or patient bed days not reducing as expected, which risks the scale of benefits achieved being less than anticipated in this report.
- Knock on implications for other health and care (including informal care) services exceeding the savings generated through reduced bed days. Currently it is impossible to estimate what the knock-on implications elsewhere in the system may be; there is a risk of costs being incurred by other organisations which they are not set up to meet, and/or demand leading to increased waiting times for service access.

3.81 We recommend monthly updates to the risk log. Monitoring and mitigation of risk would be managed via the same levers as quality management. The project director would monitor risks and escalate any that exceed project tolerances or threaten project delivery to the dedicated governance board.

Monitoring and evaluation

3.82 Routine monitoring regarding the roll-out and implementation are vital for any programme of this scale and nature. In addition, independent evaluation of the intervention during the four years of its duration will be crucial, to ensure that learning is generated and shared regarding good practice and effective implementation (to feed back to policy makers and acute care providers) as well as pitfalls to avoid and key enablers for success. Monitoring and evaluation are also vital to evidence the extent to which anticipated outcomes and impacts are realised, and any knock-on implications elsewhere in the health and social care system or for the workforce, patients and/or their families (including any unanticipated and/or negative outcomes that may emerge).

Monitoring of training implementation (progress)

- 3.83 Monitoring needs to happen at a national level. Initially, monitoring is vital regarding the achievement of key milestones during the set-up phase of the project. Specific monitoring activities that we recommend are outlined below, alongside suggested leads and metrics.

Table 3-3: Recommended minimum monitoring activities to be undertaken during the scoping and design phase

| Monitoring area/focus | Metrics |
|--|---|
| Project team recruited | Recruitment materials developed and publicised Recruitment interviews held and candidates appointed Staffing levels in the project team |
| Trainers recruited and trained | Number of applicants to become trainers Number of trainers recruited Number of sessions booked and delivered to train the trainers Attendance at train the trainer sessions (e.g. to ensure 100% training of trainers) Expected reach of each trainer |
| Feedback from trainer sessions | Short self-completion survey post-training Explore confidence, knowledge development and general reflections on the utility and relevance of the training, as well as any further support needs / barriers to implementation of the learning |
| Promotional and awareness raising activity regarding the programme | Number of communication materials produced Number of emails sent to Trusts Social media monitoring Enquiries received by the programme team |
| Trusts and clinicians booked to receive training | Number of bookings – nationally, by region, and by Trust, as well as by type (AMU/SAU) Numbers of sessions booked relative to AMU/SAU staffing levels in each Trust |
| Pilot training feedback | Short self-completion survey, undertaken pre- and post- training, exploring confidence, knowledge and willingness to undertake goals of care conversations with patients approaching end of life, as well as feedback regarding the quality of the training |
| Programme and tool design progress and completion against milestones | Milestones log Action plan Monthly monitoring |

Source: SQW

- 3.84 During the main phase of training roll-out, we recommend that the following monitoring information be captured and reviewed, to ensure progress continues as planned, and to identify any emerging slippage or issues.

Table 3-4: Recommended minimum monitoring activities regarding the training, to be undertaken during the main implementation phase

| Monitoring area/focus | Metrics |
|-------------------------|--|
| Take up of the training | Number of training sessions delivered – nationally, by Trust, by unit and by grade, compared to AMU/SAU staffing levels, and compared to roll-out plan |

| Monitoring area/focus | Metrics |
|--|---|
| Trust engagement (and reasons for any disengagement) | Feedback from Trusts/units unwilling to participate in the training |
| Feedback regarding the training | Short self-completion survey, undertaken pre- and post- training, exploring confidence, knowledge and willingness to undertake goals of care conversations with patients approaching end of life, as well as feedback regarding the quality of the training |
| Trainer capacity | Number of training sessions delivered per trainer, compared to expectations and their capacity |

Source: SQW

- 3.85 The monitoring plan requires early development of a detailed project plan with key dated milestones and leads identified for each phase. The advisory group, working alongside key NHS England & NHS Improvement leads, would be well placed to undertake this role.

Monitoring of intervention implementation (goals of care conversations)

- 3.86 Documenting the occurrence of conversations and the goals of care agreed with the patient would support both monitoring of the intervention's rollout and aid any evaluation work undertaken. Key monitoring and evaluation processes¹⁰⁰ would need establishing from the outset, to ensure learning is captured and used to inform implementation on an ongoing basis.
- 3.87 Suitable monitoring metrics must be devised in collaboration between the development group and governing body. The table below sets out the recommended minimum monitoring data to be collected regarding implementation of the intervention.

Table 3-5: Recommended minimum monitoring activities to be undertaken regarding implementation within Trusts

| Monitoring area/focus | Metrics |
|---|--|
| Goals of care conversations | Numbers of conversations held, numbers with each patient, who conducted the conversation, by Trust and department/ward Demographic data regarding patients in receipt of the intervention |
| Non-implementation rates | Numbers of patients eligible but decision taken not to undertake a goals of care conversation, nationally, by Trust and unit, with reasons noted |
| Patient refusals | Numbers of patients declining conversations (with reasons noted where freely provided) |
| Documentation of patient goals | Numbers of care plans developed, number of plans per patient |
| Patient goals, including a patient's preferred place of death and treatment preferences | Tick-box monitoring data, captured by Trust, unit and patient condition/demographics |
| Plan dissemination | Tick-box monitoring data regarding which roles/organisation each plan has been shared with (for example, primary / community or social care, or other acute units) Patient/carer access to their plan |

¹⁰⁰ Including: defining anticipated measures of the intervention's outcomes and benefits; setting timeframes within which these are intended be realised; and establishing processes and systems for data collection, to monitor both implementation and outcomes.

| Monitoring area/focus | Metrics |
|-------------------------|---|
| Conversation monitoring | How long each conversation took; who conducted the conversation; date of completion; time since admission to the unit |

Source: SQW

- 3.88 Monitoring data should be uploaded by staff electronically where possible by completion of a standardised template (we recommend the information be captured monthly, and returned directly to NHS England & NHS Improvement), as this both greatly reduces the administrative burden of data collection and submission, and helps to ensure data entered by staff is in a consistent format. Monthly returns will enable missing or incomplete responses to be quickly identified and mitigation put in place.

Measuring outcomes and impacts

- 3.89 Measuring the impact of the intervention will be important for understanding the full extent of the benefits realised by patients and by the healthcare system.
- 3.90 The studies examined in this review demonstrated a reduction in hospital bed days among end of life patients undertaking goal planning conversations. The **number of days spent in hospital following receipt of a goals of care conversation** is therefore a key impact measure that should be explored in any evaluation work.
- 3.91 In addition, there are further potential impacts that studies in this area have explored that would also be worth examining. These are presented in the table below.

Table 3-6: Recommended outcomes monitoring approach

| Impact / outcome area | Indicator/metric |
|-------------------------------------|--|
| Staff experience | Staff confidence and willingness to engage patients and families/carers in conversations about end of life care and place of death |
| | Staff capacity to undertake the conversations and associated monitoring |
| | Impacts on staff morale |
| Patient and family/carer experience | Patient and family/carer experience of care |
| | Patient and family/carer sense of control over decisions regarding their care |
| | Patient and family/carer wellbeing and quality of life |
| | Patient and family/carer feel that they 'own' their care plan |
| Service use and clinical outcomes | Patient and family/carer feel they have enough information to meaningful engage |
| | Emergency readmissions within 30 days of discharge |
| | Intensive care admissions not resulting in discharge from the unit |
| | Patients' actual place of death (compared with the preferred place of death recorded in their plan). |

Source: SQW

- 3.92 As noted earlier, the studies upon which this recommendation is based did not examine patients' subsequent use of non-acute services (such as primary, community, hospice and/or social care), or impacts on family members and informal carers. Consideration should be given to means of tracking patients' use of other services following receipt of a goals of care

conversation, to examine whether any reductions in secondary care utilisation are being offset by increased uptake of other services¹⁰¹.

- 3.93 Consideration should also be given to the establishment of a **comparator group**. A phased rollout may enable the same outcome and experience metrics listed above to be collected from a non-intervention cohort of patients in later implementer sites who are of a similar profile to those receiving goals of care conversations. Differences between the intervention group and this comparator group could then be observed.
- 3.94 Alongside monitoring information, it will be critical to explore the qualitative impacts and learning emerging regarding the intervention. For example, formative and process learning regarding the effectiveness of its design and implementation, including:
- Identifying any pre-conditions or critical success factors for effective implementation and outcomes realisation, as well as any key contextual factors, at local and national levels.
 - Capturing details of challenges, how these have been overcome, and any barriers to effective implementation and outcomes realisation.
 - Staff experience of the training, conversations and monitoring.
 - Reflections on the training and conversation tools and their utility.
 - Any suggested improvements, and aspects working particularly well.
- 3.95 This feedback could be captured via focus groups or in-depth discussions/interviews with a sample of clinicians involved in implementing the conversations, as well as with trainers and the project manager/coordinator. It may also be appropriate to capture insights from families/patients as part of this process. We recommend capturing this feedback at a mid-point in the process, to inform refinement of the approach.
- 3.96 Please refer to the Project Initiation Document in Annex D for further details regarding the monitoring and evaluation approach recommended.

¹⁰¹ As with phase one, if demand on other services were to increase then consideration should be given as to how sufficient funding could be reallocated to support the services experiencing an increase in demand.

4. Conclusions and recommendations

- 4.1 In 2016 *A Long and Winding Road* identified the need to improve communication between clinicians and patients in the NHS, making a clear case for the experiential and outcome benefits associated with effective communication. The report also identified priority challenges to be addressed and suggested potential means of doing so.
- 4.2 This review set out to develop the case further, identifying an improvement proven to a sufficient extent (in terms of clinical, experiential and financial outcomes) for a recommendation to be made to NHS England & NHS Improvement for implementation within the NHS.
- 4.3 Evidence collected and examined by this review highlights the importance of effective clinician-patient communications, including the substantial benefits that patients, the taxpayer and the healthcare system stand to realise from improved communications.
- 4.4 In broad terms three key themes emerged clearly from the review of the research base into the impact of improvements in clinician communication:
- First, there is a substantial body of evidence demonstrating that investing in improved clinician communication with patients can make a significant positive difference to patient experience, while also benefiting both patient clinical outcomes and reducing financial demands on the health system. In other words, through introducing interventions to improve communications with patients, those patients have a better experience of their care and place less demand (or less expensive demand) upon the health service.
 - Second, the evidence for all three benefits – experience, clinical outcomes and overall expenditure ('triple impact') – derived from investing in improved clinician communication is most compelling in the case of interventions relating to end of life care. These studies demonstrate that benefits can be realised by improving conversations about choices relating to medical intervention, care and support wishes and preferred place of death. The research suggests that patients have a much better end of life experience as a result of being given greater insight and input into the choices over their care plan. This in turn feeds into patients placing fewer demands on the healthcare system.
 - Third, there is evidence that suggests other areas of clinical practice might also realise positive outcomes through improving clinician communication to patients. In these other areas there was a shortage of trials demonstrating the 'triple impact' (patient experience, clinical benefit, system expenditure) standard set by this research review. It is reasonable to anticipate, however, that trials in these other areas, established with requisite evaluation methodologies, might well also demonstrate that intervention to improve communication would achieve all three benefits.
- 4.5 Goals of care conversations would be an innovative intervention not previously implemented within the NHS at scale. The evidence reviewed here demonstrates that were such conversations to be held and their outcomes documented, this would offer significant benefits

to both patients (ensuring their wishes are more widely recognised and adhered to, improving their wellbeing and reducing their time spent in critical care) and the NHS (freeing up acute beds) – with the scale of these benefits expected to far outweigh the costs.

- 4.6 Not only do these conversations have potential to significantly improve patient experience and outcomes, they would also support NHS England & NHS Improvement in delivering several of its key strategic priorities. This includes the strategic aims of the Long Term Plan to greatly expand the choice and control patients have over their care (including during end of life) by rolling out the NHS Personalised Care model to 2.5 million people by 2023/24¹⁰².

Recommendations

- 4.7 Based on the findings of this research, we recommend that NHS England & NHS Improvement adopts a phased approach to implementing this intervention. This would involve first undertaking **proof-of-concept** work at a ‘demonstrator’ site, testing and examining the outcomes and implications of this intervention within its intended setting. Following positive evaluation and testing, we recommend that **full implementation** would commence across the NHS in England.

Proof-of-concept

- 4.8 In the short-term, we recommend that NHS England & NHS Improvement:
- Identifies a Trust willing to act as a ‘demonstrator’, implementing goals of care conversations locally to generate the proof-of-concept.
 - Closely monitors and evaluates progress and outcomes of the proof-of-concept work at the demonstrator Trust. This evaluation should produce conclusive evidence that the approach set out in this report works in a present-day NHS context (evidence that could then be used to help secure buy-in from other Trusts during subsequent years), as well as learning on the practical steps that need taking to make this intervention operational and deliverable within a secondary care setting.
 - Works with stakeholders to more precisely model the implications of patients who receive the intervention spending fewer days in hospital, including the full impacts on Trust service utilisation, cost bases and income. This modelling would feed into both evaluation of the proof-of-concept work, and subsequent evaluation throughout the lifetime of the national intervention.

Full implementation

- 4.9 We then recommend that following successful delivery and evaluation of the above proof-of-concept work NHS England & NHS Improvement commences full implementation of this intervention across the NHS in England. This would entail:

¹⁰² Long Term Plan published [here](#) and Universal Personalised Care guidance (which details the NHS Personalised Care model) published [here](#).

- Introducing goals of care conversations with eligible patients presenting in AMUs and SAUs, with clinicians capturing patients' values, goals, priorities and preferences in a single care planning document.
- Introducing annual refresher training for staff to ensure their skills and knowledge remain up-to-date, and that staff rotations and departures do not deplete the necessary capabilities within any individual Trust.
- Forming a development group comprising clinical and academic experts and patients to continue to more fully develop the recommended intervention, establish a 'train the trainers' team, create a faculty of trainers and simulated patients, and roll out a training programme for clinical staff.
- Establishing dedicated project governance with responsibility to oversee national rollout of this major intervention, including monitoring both rollout and delivery of training, and the implementation of goals of care conversations with patients. The project board should report into the existing End of Life Care Programme Board. A dedicated project director and coordinator should be appointed to manage the development and implementation of the project.
- Recording the occurrence of conversations and the goals of care electronically, to both support monitoring of the intervention's rollout and to aid evaluation work. Suitable monitoring metrics are to be agreed by the project board but we recommend they capture, as a minimum, costs and savings, evidence of the rollout and implementation of the intervention, details of care plans produced, patient experiential and clinical outcomes, and service use.
- Undertaking independent evaluation of the intervention during the four years of the project, to ensure lessons are learned on good practice and effective implementation (to feed back to policy makers and acute care providers) and to produce evidence on the extent to which anticipated outcomes and impacts are realised. Key monitoring and evaluation processes would need establishing from the outset, to ensure learning is captured and used to inform implementation on an ongoing basis. Formative and process learning should be captured to inform refinement and phase two activities. It is vital that the knock-on implications for the health and social care system (and for family members and informal carers) are captured, to evidence the true economic costs and implications associated with delivering the intervention.
- Following successful implementation of the intervention within AMUs and SAUs, launching a subsequent implementation phase to expand this intervention to cover other patients identified as being at risk of dying within the next 12 months who might similarly benefit (including those on respiratory, cardiology and elderly care wards).
- Using the evaluation insights and evidence reviewed as part of this study to inform the development of other interventions to improve clinician communication with patients, for testing and trialing within NHS contexts.

5. Acknowledgements

5.1 We would like to thank all those without whose time, guidance and insights this study could not have been completed:

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Annex A: Literature search protocol

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|------------------------------------|--|
| Study title | Business Case for Improved Communication between Health Care Professionals and Patients |
| Research aims | This study will identify interventions to improve communications that have the potential to improve patient experience and generate cost savings, developing two or three into business cases. |
| Literature review questions | <ul style="list-style-type: none"> • To what extent is there a need to improve the way healthcare staff exchange information and communicate with patients? <ul style="list-style-type: none"> ➢ What existing problems could be addressed by better communications? • What are the potential benefits of any improvement(s)? <ul style="list-style-type: none"> ➢ Reduced demand for services? e.g. fewer care interactions, drugs/equipment provided to patients, fewer emergencies, improved/increased self-management ➢ Improve staff morale/retention (and therefore reduced hiring and training costs)? ➢ Improved patient experience? ➢ Longer-term impacts? Such as reduced insurance premiums for Trusts/CCGs, reduced litigation • What interventions/changes would make, or are likely to make, the biggest impact? <ul style="list-style-type: none"> ➢ And what sort of impacts do they make? • How can the effectiveness of communication be measured and/or assessed/rated? <ul style="list-style-type: none"> ➢ Including any benchmarks or standardised tools for measuring the quality of communications or the impact of improved communications ➢ To what extent have these been used, and what is the effectiveness when used, in healthcare settings? • What evidence exists tying improved scores/metrics to reductions in service use, litigation, or other cost savings? |
| Period | 2008 – Present |
| Geography | <ul style="list-style-type: none"> • UK (including national, home nations, regional, local) • Comparator countries (US, Australia, Canada, Australia, New Zealand, France, Netherlands, Germany, Sweden, Belgium, Norway, Japan) |
| Language of publication | <ul style="list-style-type: none"> • English |
| Types of document | <ul style="list-style-type: none"> • Research reports • Journal articles • Evaluations |
| Databases searched | <ul style="list-style-type: none"> • British Nursing Index (BNI) • CINAHL (Cumulative Index to Nursing and Allied Health Literature) • EMBASE • Health Business Elite • HMIC • The Department of Health Library and Information Services database • The King's Fund Information and Knowledge Services database • PubMed |

| | | | | | |
|---------------------|--|--|---|--|--|
| Search terms | <p>patient cue* cue* prompt sheet teach back chunk and check value statement* intervention* support advice advise inform* guid* personalis* care plan* self-manage* self-care behaviour* person-centred shared decision* motivational interview* social prescribing active signposting risk communication health literacy support* training decision aid information leaflet treatment summary</p> | | <p>patient communication* doctor communication* doctor-patient patient-doctor NHS palliative cancer doctor* nurse* occupational therap* GP* general practice physician* consultant* primary care secondary care community service* community healthcare mental health CAMHS inpatient* outpatient* long-term condition* LTC* chronic disease* health coach*</p> | | <p>impact outcome* saving* measur* Press Ganey Roter Method CQI-2 patient recall satisfaction empower* quality improve* efficacy burnout patient adherence patient compliance adherence compliance safety error* medication error* complaint* medico-legal litigat* tariff</p> |
|---------------------|--|--|---|--|--|

Annex B: Bibliography

- B.1 All 84 documents that were reviewed in full are listed below in the section titled 'document shortlist'. The 35 documents that clearly demonstrated their interventions delivered improvements are highlighted in bold.
- B.2 Additional evidence subsequently identified by the advisory group during the detailed development of this report's recommendations is also included in this annex, under the heading 'additional evidence'.

Document shortlist

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Annex C: Data, calculations and assumptions underpinning the proposed intervention

- C.1 This annex supports the substantive paper setting out the headline case for investing in goals of care conversations during end of life care. It is informed by our review of international evidence regarding interventions to improve communication between healthcare practitioners and patients.
- C.2 This paper outlines the key assumptions made and supporting evidence underpinning the headline case, to provide further detail regarding our methodology and the datasets used.
- C.3 Note that figures included in this technical annex have all been rounded for the purposes of reporting. If a number is 1,000 or greater, it has been rounded to the nearest whole integer. If a number is under 1,000, it has been rounded to 2 decimal places (as most smaller numbers detail financial information). All total figures reported for costs and savings (e.g. the estimated overall financial impact of the intervention) are based on calculations made using the original, non-rounded figures, not the rounded figures stated in this report.
- C.4 All financial estimates are provided at 2019/20 values¹⁰³, unless stated otherwise. Where any estimates are based on cost data from previous financial years (e.g. the cost of an excess bed day), inflation of 2.1% per annum has been applied to produce a 2019/20 estimate for use in our calculations.

Supporting evidence

- C.5 The headline case has been informed by three key trials that tested the impact of three personalised end of life care planning interventions:
- Abel, J., Pring, A., Rich, A., Malik, T., & Verne, J. (2013), "The impact of advance care planning of place of death, a hospice retrospective cohort study", *BMJ Supportive & Palliative Care* 00, pp.1-6.
 - Ahrens, T., Yancey, V., & Kollef, M. (2003), "Improving Family Communications at the End of Life: Implications for Length of Stay in the Intensive Care Unit and Resource Use", *American Journal of Critical Care* 12:4, pp.317-324.
 - Orford, N., Milnes, S., Simpson, N., Keely, G., Elderkin, T., Bone, A., Martin, P., Bellomo, R., Bailey, M., & Corker, C. (2017), "Effectiveness of communication skills training on outcomes in critically ill patients with life-limiting illness referred for intensive care management: a before-and-after study", *BMJ Supportive & Palliative Care* 0, pp.1-7.

Intervention

- C.6 As the headline case is based on a blended mix of three articles, we have created our own inclusion and exclusion criteria for the patient cohort, in discussion with the advisory group

¹⁰³ The financial year within which this modelling was originally undertaken.

and Steering Group members. Following a successful proof-of-concept intervention, care planning conversations would take place in all AMUs and SAUs across England, carried out with all admitted patients who are identified as being at increased risk of serious clinical deterioration and death during their presentation¹⁰⁴ and/or at risk of dying within the next 12 months¹⁰⁵.

- C.7 A frontline clinical member of staff - CT2s, ST2s, charge nurses, advanced nurse practitioners and band 6 or 7 physiotherapists and occupational therapists – would hold a conversation with each patient (and/or their family/carer as appropriate). This trained staff member would provide medical updates, guidelines for care, and explain the care options available to the patient (including and in addition to curative care), then discuss the patient’s values, treatment options and preferences with the patient and/or their family (depending on who is available and able to participate – ideally both).
- C.8 The staff member would use a planning document to capture the patient’s values, priorities and treatment/care preferences. This would be a live document, created during the first conversation and updated (if necessary) during subsequent conversations. Patients and their families would keep a paper version for their own ongoing use/reference. Staff would also record key outcomes and decisions made in their organisation’s electronic system.
- C.9 Once implementation within AMUs and SAUs has been completed and goals of care conversations in these settings have been routinised, and following successful evaluation, this study’s advisory group has recommended that the approach could be extended to respiratory, cardiology and elderly care wards within acute providers. This rollout (phase two) would use the same training and implementation approach but informed by learning emerging from the evaluation of implementation within AMUs and SAUs (phase one).
- C.10 The costs of training these staff, and of freeing up time for them to subsequently hold the care planning conversations with patients, are set out in the ‘Implementation costs’ subsection of this annex.

Data sources, assumptions and calculations

Optimism bias

- C.11 Some of the calculations used to produce the costs and benefits detailed in this annex are based on data that are incomplete, relatively old and/or not fully representative. Adjustments for optimism bias have therefore been applied to several estimates of cohort sizes and scales of impact, to help ensure that the potential costs of this intervention are not underestimated and that potential impacts are not overestimated. Where adjustment for optimism bias has been applied to any numbers set out in this annex, the size of the adjustment has been stated.

¹⁰⁴ Using the National Early Warning Score (NEWS) 2 screening tool.

¹⁰⁵ Using their frailty score, the Supportive & Palliative Care Indicators Tool (SPICT) and the Gold Standards Framework (GSF).

Potential patient numbers

C.12 Based on the above inclusion criteria we have calculated the potential number of patients affected by the intervention. It is not possible precisely to calculate the exact size of the relevant patient cohort using NHS England & NHS Improvement Hospital Episode Statistics (HES) data, so the figures below are a best estimate based on the available evidence.

Phase one

C.13 To estimate the number of potential patients that the first phase of the intervention may affect we first sourced data on admissions to AMUs. We have triangulated estimates from two sources:

- AMU admissions estimates from University Hospital Southampton¹⁰⁶, which receives roughly 30 to 50 admissions per day¹⁰⁷.
- A Society for Acute Medicine (SAM) audit of 127 AMUs in the UK, which found AMUs studied admitted a median number of 45 patients per day¹⁰⁸.

C.14 As the SAM audit's median number of 45 admissions per day falls within the range published by University Hospital Southampton, and is calculated from a more representative sample, we have estimated that **AMUs receive 45 admissions per day**.

C.15 Data on admissions to SAUs was drawn from a study by Mohamed and Mufti¹⁰⁹. This study monitored the number of patients who attended an SAU over a period of eight weeks (56 days). During this study period, 550 patients attended. Using this, we have estimated that **SAUs receive an average of 9.82 admissions per day**¹¹⁰.

C.16 To estimate the annual number of national admissions to AMUs and SAUs, we have multiplied our estimates of daily admissions by the number of days in the year (365) and by the number of Trusts in England (152). This assumes all Trusts have one AMU and one SAU. This gives **estimated annual admissions to AMUs of 2,496,600 and to SAUs of 544,893**. With **optimism bias** of -2% applied to AMU admissions and -10% to SAU admissions¹¹¹, to account for the age and representativeness of the data used to produce each of these estimates, these **numbers are reduced to 2,446,668 and 490,403** respectively.

C.17 To calculate the number of these admissions who will be eligible for the proposed intervention, we used the findings of a Gardiner, Gott and Ingleton study from 2012¹¹². This study surveyed patients in two UK acute hospitals and found 36% met Gold Standards Framework (GSF) criteria. With optimism bias of -12 percentage points applied, to account

¹⁰⁶ The only data we could find identify that detailed actual numbers of admissions seen at any Trust.

¹⁰⁷ Published [here](#).

¹⁰⁸ SAM audit published [here](#). The report does not state a mean number of admissions per day.

¹⁰⁹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1079231/>

¹¹⁰ This figure has not been rounded. An SAU can obviously only admit a whole number of patients per day, but rounding this figure of 9.82 up to 10 would artificially inflate multiple subsequent calculations that have been used to produce our estimates of potential savings (as an average of 10 patients per day would mean a higher total number of patients per year than this 'true' average of 9.82 per day).

¹¹¹ Further optimism bias to reflect that the audits capture a snapshot of a point in time, which might not be accurate for others points in time during the year. However, the AMU audit was conducted during the summer; given emergency admissions are lowest in the summer, it has been assumed that the AMU audit has likely captured data at a period of relatively low admissions, and so the figures presented here are not likely to be over-estimating average patient inflows. The SAU audit took place during the winter, although that is the smaller of the two.

¹¹² Published [here](#).

for the age and representativeness of Gardiner et al’s study, we have conservatively estimated that **24% of AMU and SAU admissions** will be patients at increased risk of serious clinical deterioration and death during their presentation and/or at risk of dying within the next 12 months. This gives an estimated total of **704,897 admissions to AMUs and SAUs per year who meet GSF criteria**. We have developed the cost figures on the basis that each of these 704,897 admissions will require one initial and one follow up goals of care conversation.

Phase two

To estimate the number of potential patients that phase two of the intervention may affect we have used HES data (Hospital Admitted Patient Care Activity, 2017-18). We collated figures on the number of admissions by treatment specialty (see **Error! Reference source not found.** below).

Table C-1: Number of admissions by treatment specialty, 2017-18

| Treatment specialty | | Admissions |
|---------------------|--|----------------|
| 320 | Cardiology | 424,752 |
| 340 | Respiratory Medicine (Thoracic Medicine) | 231,084 |
| 430 | Geriatric Medicine | 283,740 |
| Total | | 939,576 |

Source: NHS Hospital Episode Statistics, Hospital Admitted Patient Care Activity, 2017-18

The Milnes et al study we used to estimate the proportion of AMU/SAU patients likely to meet GSF criteria was conducted using a population of patients admitted to acute hospital beds, not restricted to any particular patient groups or units/wards within the hospital examined. We have therefore again made our calculations based on an assumption that 24% of the acute admissions detailed in **Error! Reference source not found.** will be patients who meet GSF criteria. This means the estimated number of **eligible patients across all three wards (cardiology, respiratory and elderly care) totals 225,498**.

Implementation costs

Faculty development

- C.19 Based on steer from the study’s advisory group, a high-level plan for the faculty development processes has been devised, including full design of the intervention itself, recruitment of trainers and simulated patients, and design and delivery of the train the trainer programme. The team roles considered necessary by the advisory group, and assumptions made about their time input and costs, are set out in Table C-2 below.

Table C-2: Projected faculty development costs

| Role | Assumptions | Annual cost |
|---|---|----------------|
| Development group develop intervention in full detail | 8 development group members spend 2 days each | £14,000 |
| Train the trainers team develop training programme | 8 team members spend 2 days each | £14,000 |
| Process to recruit trainers | Two team members spend half a day of time each on recruiting each successful trainer | £8,750 |
| Delivery of train the trainer programme | 2-day programme. Delivered by two team members and attended by all trainers | £21,000 |
| Briefing of simulated patients | Half-day briefing. Delivered by two team members and attended by all simulated patients | £4,625 |
| Team provide ongoing support to trainers | 2 days per month | £21,000 |
| Total | | £83,375 |

- C.20 Each individuals' time has been costed at the following day rates: **development group and 'train the trainers' team members (£750); trainer (£750); simulated patient (£250)**. In addition, **£125 per day for travel and expenses** has been added to each day rate where travel is expected to be required.
- C.21 The costs listed above involve external (non-NHS) procurement. Some may therefore attract VAT. Exactly which costs will and won't attract VAT depends on the contractors used (currently unknown); **VAT has therefore not been factored into our calculations.**
- C.22 All faculty development costs (except time spent developing the train the trainer programme) are assumed to continue to be incurred in subsequent years of implementation, to continue recruiting and training/briefing new trainers and simulated patients to mitigate against turnover. We have estimated that in **subsequent years these costs will halve, giving a total of £27,688 per year needed for faculty development in subsequent years.**
- C.23 **In phase two, we have estimated these recurrent faculty developments costs to be £41,531 per year** (1.5x the recurrent phase one costs, reflecting that phase one covers two units per Trust while phase two covers three wards per Trust). This would support the additional trainers and simulated patients needed to deliver the additional training required for specialist ward staff). **Phase 2 costs do not include any costs associated with continuing to deliver phase 1 concurrently; e.g. they would be in addition to any ongoing phase 1 costs.**

Training for clinicians

- C.24 Initial assumptions were made that backfilling would be required for clinical staff undertaking training. Discussions with an English Trust subsequently led to the conclusion that such costs were not routinely backfilled and our calculations should be prepared on that basis. These costs were therefore removed from our calculations and excluded from estimates of the overall and phased costs of implementing this intervention (i.e. they represent the 'true'

opportunity cost of preparing for implementation but are assumed to not require any financial outlay). For completeness, the following clauses in this subsection set out the opportunity costs which have not been included in the financial calculations.

- *During phase one, several staff from AMUs and SAUs will need to be trained on conducting and recording the outcomes of goals of care conversations. We are proposing that consultants and matrons will need to attend a two-hour briefing, whilst CT2s, ST2s, charge nurses, band 6 or band 7 advanced nurse practitioners, band 6 or 7 occupational therapists and band 6 or 7 physiotherapists will need to attend a 2-day modular training course, plus a follow up half-day refresher session a few months later.*
- *To calculate the number of staff that will need to undertake the training, we first sourced data on the composition of AMU teams. RCP guidance on staffing an AMU¹¹³ sets out a recommended AMU shift rota that would ensure minimum consultant coverage is met at all times. To meet this suggested rota it recommends that 10 consultants would be needed on an AMU's roster. Equivalent guidelines for other staff roles, however, are not available.*
- *To estimate the number, we have used figures from the SAM audit cited earlier in this annex. The audit provides figures on the median number of staff who are present in an AMU at any one time, broken down by staff role. The median number of consultants the SAM audit found on an AMU floor at any given point in time was three – approximately one-third of the 10 recommended by RCP guidelines. We have therefore assumed that all AMUs will have 3x the number of consultants on their rosters that are physically present on the unit at any one point in time and, in the absence of guidelines on shift rotas for other roles, that AMUs will also have 3x the number of other staff (charge nurses, CT2s etc.) on their rosters as they do working in the unit at any one time.*
- *We have therefore taken the median number of staff in each role, and multiplied each by three to calculate the estimated number of clinical staff on each AMU's staff roster. These calculations produce an estimated national total of 1,824 consultants and matrons who will need to attend a two-hour briefing, and 3,648 staff in other roles who will need to attend training sessions.*
- *In the absence of any published data, research or guidelines on SAU team composition we have assumed that the number of staff in AMUs is mirrored in SAUs. Therefore, we have estimated that 3,648 AMU and SAU consultants and matrons across England will need to attend the briefing and 7,296 AMU and SAU staff will need to attend the training session.*
- *Using data from a variety of sources on medical professional salaries (set out in Table C-3 below), we have calculated the true opportunity cost of consultant and matron staff attending the briefing sessions and the ST2s, CT2s, charge nurses, band 6 or band 7 advanced nurse practitioners, band 6 or 7 occupational therapists and band 6 or 7 physiotherapists attending the full training programme.*

¹¹³ Available [here](#).

Table C-3: Salary costs (excluding on costs) of relevant clinical staff

| Staff role | Salary | Contracted hours per week |
|---------------------------------|------------|---------------------------|
| Consultant | £91,477.50 | 48 |
| Matron | £47,713.00 | 37.5 |
| CT2 | £42,161.50 | 48 |
| ST2 | £42,161.50 | 48 |
| Charge nurse | £37,877.00 | 37.5 |
| Advanced Nurse Practitioner | £33,906.25 | 37.5 |
| band 6-7 occupational therapist | £33,985.50 | 37.5 |
| band 6-7 physiotherapist | £33,985.50 | 37.5 |

Source: consultant salaries [here](#), matron salaries [here](#), ST2 and CT2 salaries [here](#), charge nurse salaries [here](#), advanced nurse practitioner salaries [here](#), occupational therapists and physio therapist salaries both [here](#).

- Using these data, we have calculated that the opportunity cost of covering senior staff members' time (consultants and matrons) whilst they attend the briefing, using staff of the same cost, would be £245,176 for all 152 Trusts¹¹⁴.
- We have calculated that each Trust would need to send the following numbers of staff to attend two-day training programme (plus 0.5-day follow-up refresher session) to ensure full coverage in both their AMU and SAU: six ST2s, 12 CT2s, 12 charge nurses, six advanced nurse practitioners, six occupational therapists and six physiotherapists.
- It is estimated that the opportunity cost of providing backfill for these staff, with staff of the same cost, whilst they attend the two-day training programme (plus 0.5-day follow-up refresher session) would have been £2,561,630 for all 152 Trusts¹¹⁵. This assumes full engagement in both days of training, and the half-day refresher session, by all AMU and SAU staff, with 100% backfill cover being provided.

Phase two

To calculate the number of staff that will need to undertake phase two training, we first sourced data on the composition of specialist ward teams. The basis for these calculations was an RCP audit examining respiratory ward staffing levels¹¹⁶, which gives figures on the median number of staff present in a respiratory ward at any one time, broken down by staff role. Using the same assumptions applied to calculate phase one staffing levels, we have assumed respiratory wards have 3x the number of staff in any one role on their rosters as they do physically present on the ward at any one point in time.

In the absence of data or audits for staffing levels of cardiology or elderly care wards, we have assumed these wards are staffed with the same number of staff, in the same roles, as respiratory wards.

¹¹⁴ These and other backfill costs may be higher if bank or agency staff are used. On costs not included.

¹¹⁵ As above, these and other backfill costs may be higher if bank or agency staff are used. On costs not included.

¹¹⁶ Available [here](#).

These calculations give us an estimated staff roster for each ward of: 6x CT2; 6x ST3; 9x specialist nurse; 3x specialist physiotherapist; and 12x specialist consultant. This means an estimated national total of 5,472 consultants who will need to attend a two-hour briefing, and 10,944 staff in other roles who will need to attend training sessions.

Using the salary costs (excluding on costs) set out Table C-3, plus additional data on ST3¹¹⁷ and nurse specialist¹¹⁸ salaries and working hours, this gives total backfill opportunity costs of £401,094 for all phase two staff attending briefings, and £3,617,421 for all phase two staff attending training sessions.

Training for clinicians – procuring training sessions

- C.25 To calculate the potential costs of procuring sessions, we have made the following assumptions (recommended by the advisory group):
- One day of a trainer’s time costs £750 (plus £125 expenses per day).
 - One day of a simulated patients’ time costs £250 (plus £125 expenses per day).
 - Each training session is delivered by a trainer and two simulated patients. Each clinical staff member attending the full training programme attends two full-day sessions plus one half-day follow-up refresher session.
 - Briefing sessions at each Trust are delivered over the course of one day. One trainer visits the Trust and holds 2-3 sessions throughout the day, with each session lasting two hours. All AMU and SAU consultants and matrons are able to attend one session on this day.
- C.26 We have also costed for 0.25 days of a trainer’s time to familiarise themselves with each AMU or SAU’s planning documentation and data reporting systems prior to delivering training to staff working on that AMU/SAU (0.5 days for preparation time in total per Trust). This has been costed at a rate of £750 per day for the trainer’s time (excluding travel and expenses, as we assume this task would be undertaken remotely).
- C.27 Using above assumptions about the cost of trainers’ time and their required input, we have **estimated that the cost of all 152 Trusts receiving two-hour briefing sessions with senior staff (all consultants and matrons in AMUs and SAUs) would total £133,000. Procuring training sessions for all staff (including paying for trainers’ time to familiarise themselves with unit documentation and reporting systems) would cost an additional £3,705,000.**

Phase two

For phase two we have made the same assumptions about the costs of trainers’ and simulated patients’ time, and about the length of each training session and briefing session.

¹¹⁷ ST3 salary and working hours estimated to be £47,132/48 hours ([here](#)).

¹¹⁸ Nurse specialists estimated to be band 6, based on job adverts found online (e.g. [here](#)). Salary and working hours of and £33,834/37.5 hours.

We have similarly costed for 0.25 days of a trainer's time to familiarise themselves with each specialist ward's planning documentation and data reporting systems prior to delivering training to staff working on that ward, meaning that for phase two this will require 0.75 days total per Trust (due to there being three specialist wards for the trainer to familiarise themselves with).

This gives a total cost of procuring phase two briefings and training sessions of £6,042,000 per year.

Planning conversations

C.29 Initial assumptions were made that clinical staff would require backfilling for time spent holding planning conversations. Early groundwork for the proof of concept work in an English Trust led to the conclusion that such costs were not routinely backfilled. These costs were therefore removed from our calculations and excluded from estimates of the overall and phased costs of implementing this intervention (i.e. they represent the 'true' opportunity cost of preparing for implementation but are assumed to not require any financial outlay). For completeness, the following clauses in this subsection set out the opportunity costs which have not been included in the financial calculations.

- *We are proposing that each eligible patient will have one half-hour initial planning conversation with a trained member of the team within the AMU / SAU, and one follow-up conversation, also lasting half-an-hour. Which staff member holds conversations with each patient will be decided on an ad hoc basis by unit staff.*
- *Using the staff salaries and contracted hours set out in Table C-4 we have calculated the per hour cost of each staff member who will be holding conversations with patients. Combining these per hour costs with our estimates of likely staff roles on each unit's roster and the likely number of staff in each of those roles, we have calculated the estimated average true opportunity cost of two half-hour conversations with a trained member of an AMU or SAU team to be £16.95¹¹⁹. If two half-hour conversations are held with all 704,897 eligible AMU/SAU admissions, these conversations would be estimated to cost £11,949,239 per year to deliver to all admissions.*

Phase two

In phase two, we are proposing that patients at risk of dying in the next 12 months will have one half-hour initial planning conversation with a trained member of the team in respiratory, cardiology and elderly care wards and one follow-up conversation, also lasting half-an-hour.

Using the same approach as for AMUs and SAUs, we have calculated that the average cost of two half-hour conversations with a trained member of the respiratory, cardiology and elderly care teams is £17.63. If two half-hour conversations are held with all 67,649 eligible specialist ward admissions, these opportunity costs would total £1,192,576 to deliver to all patients nationally.

¹¹⁹ Assuming each staff member holds the same number of conversations.

Implementation, monitoring and evaluation

- C.30 Based on discussions with an English Trust, we recommend that a senior clinical ‘champion’ is identified in each Trust, to encourage and monitor take-up of training and delivery of the intervention by clinical staff. The recommendation of the Trust and advisory group is that 0.2 FTE of input would be required from each Trust’s champion. Assuming each Trust identifies a band 8a staff member to act as its champion, this would create **an annual cost of £1,356,022 for phase one** (total cost incurred across all 152 Trusts).
- C.31 For monitoring and evaluation purposes, we have assumed that an external evaluation is undertaken/commissioned, with monitoring undertaken by NHS England. All relevant data from Trusts would need to be submitted to the national project management and evaluation teams. **Collation, standardization and submission of this data would need to be undertaken by a member of administrative staff located at each of England’s 152 Trusts.**
- C.32 We are proposing this would require 0.25 FTE input from an administrative staff member at each Trust for phase one. If band 4 administrative staff¹²⁰ were used, this would create **an annual data collation and submission cost of £801,382 for phase one.**

Phase two

We are proposing that phase two would require an additional **0.2 FTE champion** per Trust, plus an additional **0.4 FTE input from an administrative staff member** at each Trust (on top of any phase one continuing costs).

If a band 8a champion and band 4 administrative staff member¹²¹ were used, this would create an additional cost of £2,638,234 for phase two (total cost incurred across all 152 Trusts).

- C.33 An evaluation would also need to be undertaken; we recommend an independent, external evaluation. This would include analysis of data collected for the purposes of both monitoring implementation and realisation of outcomes/impacts, as well as supplementary qualitative research (to explore lessons learned on implementation processes, identify good practice and/or pre-conditions needed for success, and any reasons for differences in outcomes between patient cohorts and reporting). We have **costed this at £100,000 (excl. VAT) annually**, on the assumption that monitoring data from all Trusts is collated and analysed by the programme management team, and provided to the evaluators for their usage.

Central project management

- C.34 We recommend recruitment of a dedicated project management team to manage and monitor implementation of the training programme and subsequent rollout of planning conversations nationally.
- C.35 The advisory group has recommended a dedicated team of the size and caliber shown below, given the scale of the roll-out planned and extent of the engagement, management and

¹²⁰ Salary £21,819.

¹²¹ Salary £21,819.

monitoring required. Team roles and assumptions made about their time input and costs are set out below.

Table C-4: Estimated project management costs

| Role | Assumptions | Annual cost ¹²² |
|--|---|----------------------------|
| Recruiting to project management posts | | £20,000 |
| Project director | Band 9, 1 FTE | £111,921 |
| Project manager | Band 8a, 1 FTE | £55,758 |
| Project management support officer | Band 5, 1 FTE | £30,268 |
| Communications and engagement leads | Band 8c, 4 FTE | £308,885 |
| Communications and engagement lead | Band 8b, 1 FTE | £65,383 |
| Communications and engagement officer | Band 5, 1 FTE | £30,268 |
| Expert advisor time supporting PM team and local site engagement | 4 days per month ¹²³ , £875 p/ day | £42,000 |
| Governance ¹²⁴ | Quarterly board meetings, 1 day of time per meeting for 3x external people to attend, £875 p/ day for external people | £10,500 |
| Communications | Printing brochures, design costs etc. | £20,000 |
| Contingency | 1% of setup, project management and training delivery costs | £46,734 |
| Total | | £741,715 |

Source: SQW cost calculations; expert advisory group assessment of staffing levels and grades needed

- C.36 Some of the costs listed above involve external (non-NHS) procurement. Some may therefore attract VAT. Exactly which costs that will and will not attract VAT depends on the contractors used (currently unknown); **VAT has therefore not been factored into estimated calculations.**

Total implementation costs

Based on the above, we have calculated that the **estimated total annual implementation costs for this intervention will be £6,390,088 in phase one** and an additional £9,946,837 in phase two (2019/20 values). This includes costs for faculty development, providing briefing and training sessions, national programme management and evaluation costs, but excludes the ‘sunk’ costs of backfill for staff attending briefings and training sessions and time spent having planning conversations. Including the opportunity costs would have increased the overall annual costs of the programme from £6,390,088 to £21,146,134, which would still be expected to provide a significant return on investment

¹²² All staff for whom salary bands are stated in the ‘Assumptions’ column are assumed to all be additional/new NHS England & NHS Improvement employees. Costs therefore include salaries plus 25% on-costs (such as equipment, human resources and IT support).

¹²³ 6 days per month during the first full year of implementation (2020/21). We have assumed 2 days per month for year 1 (to support PM team during faculty development and evaluation setup) and 1 days per month from year 3 onwards (once the intervention has become established).

¹²⁴ Assuming quarterly board meetings, with external paid to attend.

Impact and savings

Nature of the impact

- C.37 We have assumed that the intervention will result in the same reduction in total bed days over a 12-month period as the reductions found by the studies used as the basis for our headline case. Considering the size and similarity of the patient cohorts examined, the most relevant evidence of a reduction in bed days over a 12-month period was found was Abel et al's study. This study found that when clinicians held advance care planning conversations with patients in palliative care, those patients spent 8.4 fewer bed days in hospital during their final year of life. Adjusting this finding of 8.4 days by -13.75% to account for optimism bias (reflecting the age, representativeness and methods of the study), we have estimated that patients receiving the intervention recommended by this review **will on average spend 7.245 fewer days in hospital in total during their last year of life.**
- C.38 However, the impact observed by Abel et al in their study would not be expected to be observed across the entire cohort of patients targeted by our proposed intervention. The reasons why are as follows:
- All of Abel et al's study cohort were in palliative care and therefore in the last year of their life.
 - This intervention, however, is targeting a broader patient cohort: acute inpatients who meet GSF criteria. Many of this cohort will have conditions that have not progressed as far and who may well live for longer than a year.
 - A 2015 study by Milnes et al¹²⁵ screened acute inpatients in an Australian hospital using GSF and then observed their outcomes over the following year. This study found that 50.3% of patients who met GSF criteria died within one year of screening, with the rest living longer.
- C.39 Applying optimism bias of -6.7 percentage points to Milnes et al's figure (reflecting the age and relatively small-scale of the study) gives an estimated 43.6% of patients who, having been screened and found to meet GSF criteria (and hence eligible for a goals of care conversation under this intervention) would be expected to die within one year of screening. It is among these 43.6% of patients that we anticipate our proposed intervention realising a bed day reduction.

Scale of impact – phase one

- C.40 We are estimating that 704,897 admissions are made to AMUs and SAUs per year (paragraph C.17). This is **not** a figure of 704,897 unique patients; some of these admissions will be patients who have already been admitted at least once previously within the same one-year period. To calculate the scale of this intervention's potential impact, we need to calculate the number of unique patients within the 704,897 admissions.

¹²⁵ Published [here](#).

C.41 This review could not identify any evidence that could be used to calculate the proportion of emergency admissions that are 12-month readmissions¹²⁶. The process we have used to estimate the proportion of the 704,987 AMU/SAU admissions who are unique patients, and the proportion of these unique patients likely to realise a bed day reduction following this intervention (see previous subsection) is set out below:

- Abel et al's study examined patients in their last year of life, and found that the average number of times each patient was admitted to hospital as an emergency during that last year of life was 1.7.
- We have therefore assumed that all unique patients who receive our proposed intervention **and** are in their last year of life will be admitted to hospital as an emergency 1.7 times per year.
- As set out in paragraphs C.41-C.43, not all patients who receive this intervention will be in their last year of life (56.4% will likely live longer). Data on the likely number of emergency admissions these patients experience per year could not be identified by this review. As these patients' conditions have not progressed as far, we have conservatively estimated that this group of patients will have an average of 1.2 emergency admissions per year.
- We have therefore assumed that among the 704,897 AMU and SAU admissions screened and found to meet GSF criteria, there will be two cohorts of patients:
 - One cohort of patients who are in their last year of life. This group will be admitted to hospital as an emergency an average of 1.7 times per year, and comprise 43.6% of all unique patients.
 - One cohort of patients who are **not** in their last year of life. This group will be admitted to hospital as an emergency an average of 1.2 times per year, and comprise 56.4% of all unique patients.

C.42 By creating the assumptions listed above, we have arrived at an estimate of 497,106 unique patients admitted to AMUs and SAUs every year. The number of patients who could reasonably be projected to spend 7.245 fewer days in hospital over the twelve months after their conversation is held is therefore **216,738 patients per year** (43.6% of the 497,106 unique patients).

C.43 Using data from NHS reference costs for 2017/18, and adjusting it for inflation, the average cost of an excess bed day in hospital is £359.98 in 2019/20¹²⁷. By multiplying the cost of a bed day by 7.245, and multiplying the resulting number by the total number of patients expected to realise a bed day reduction (216,738), we arrive at an estimated cost reduction of £565,262,134 (2019/20 values). Applying further optimism bias of -10% to this figure – to reflect the average age and reliability of the data sources and studies used to produce each of our individual assumptions - reduces this **total cost reduction to £508,735,920 for phase one (this reduction first realised in full during the second year of full implementation)**. This assumes all eligible patients receive goals of care conversation(s), and that each

¹²⁶ Existing studies and data primarily focus on 30-day readmissions.

¹²⁷ NHS reference costs 2017/18 published [here](#). An excess bed day cost £346 in 2017/18.

conversation and subsequent record of patient goals is of sufficient quality to achieve the expected outcomes.

Phase two

Scale of impact

We have estimated 225,498 unique patients admitted to the identified specialist wards annually, who meet GSF criteria (paragraph C.18). However, the advice of the advisory group is that most admissions to these specialist wards are likely to have come via an AMU or SAU. In the absence of any data or research of use for identifying the proportion of patients on specialist ward who have arrived via an AMU or SAU, for the purposes of our calculations we have estimated 'most' to be 70%.

Any patients among this 70% who could therefore be expected to realise a bed day reduction regardless of the conversations they have on the specialist ward, as they will already have had a goals of care conversation in the AMU or SAU they previously attended. This means that 30% of specialist ward admissions who meet GSF criteria could potentially realise a reduction in excess bed days due to the care planning conversation they have on the specialist ward.

Calculating 30% of 225,498 gives us 67,649 patients who might realise a reduction in bed days due to the goals of care conversation they have on the specialist ward.

As with phase one patients, we have assumed 43.6% of these eligible patients will actually realise a bed day reduction of 7.245 bed days (due to this 43.6% being the cohort that are actually in their last year of life). This gives a total of 29,461 patients realising a bed day reduction due to the goals of care conversation they have on the specialist ward, generating a cost reduction of £76,836,470 (2019/20 values). Applying further optimism bias of -10% to this figure – to reflect the average age and reliability of the data sources and studies used to produce each of our individual assumptions - reduces it to **£69,152,823 (first realised in full during the second year of full implementation)**.

Cost reduction and net savings

- C.47 Using the above figures for the reduction in bed days and the cost of excess bed days, combined with our estimate for the potential population affected by this intervention, we have estimated the potential cost reductions realised due to an annual reduction in bed days to be £508,735,920 for phase one and £69,152,823 for phase two (each first realised in full during the second year of full implementation of each phase).
- C.48 For **phase one**, once total annual implementation costs of £6,390,088 are factored in, this produces an estimated net annual saving of £502,345,833.
- C.49 For **phase two**, once total annual implementation costs of £9,946,837 are factored in, this produces an estimated net annual saving of £59,205,986.

- C.50 Note that these figures for cost reductions and savings do not take into account any other potential impacts Trusts might realise (e.g. on tariff payments received by Trusts), or additional (unexpected) costs incurred over and above those set out in these calculations.

Annex D: Project initiation document

Introduction

- D.1 The section below sets out the project initiation document for the phase one intervention. It sets out details regarding the:
- Project definition, including key objectives, scope, underpinning rationale, deliverables and critical success factors
 - Implementation plan, including details of the intervention and details of the key actors and roles involved in its implementation
 - Suggested management and oversight arrangements
 - Proposed timeline and phasing for implementation
 - Key risks and issues anticipated, and mitigation strategies recommended
 - Recommended monitoring and evaluation arrangements.
- D.2 This has been developed based on experience of other personalised care planning interventions and evaluations, as well as learning from the three studies reviewed in depth regarding end of life care, and input from the advisory group.

Project definition

Purpose and objectives

- D.3 The purpose of the phase one project is to improve communication between clinicians and patients in NHS Acute Medical Units (AMU) and Surgical Assessment Units (SAUs) in England.
- D.4 The project has been recommended to improve clinical outcomes, patient (and family/carer) experience and reduce costs incurred by the NHS in England.

Scope

- D.5 Goals of care conversations would be held with patients presenting in all AMUs and SAUs across England, who are identified as being at risk of dying in the next 12 months and/or at risk of serious clinical deterioration and death during the presentation. This will form phase one of the programme.
- D.6 These conversations – held within 48 hours of patient admission - involve providing patients with information about their condition and treatment options, and giving them the opportunity to have their values, priorities and treatment preferences both heard and respected by clinical staff. These values, priorities and preferences will then be captured in a single care planning document.
- D.7 Training and development work will be undertaken to enable clinicians to have these conversations, with annual refresher training.

- D.8 Phase two would extend delivery to three other speciality wards within all NHS Trusts in England: cardiology, respiratory and elderly care, following successful evaluation of phase one.

Rationale

- D.9 This draws on evidence from the studies and sources identified via a systematic international literature review commissioned by NHS England. In particular it is informed by studies that examined the impact of three personalised end of life care planning interventions: Abel et al, 2013; Ahrens et al, 2003; Orford et al, 2017.
- D.10 Key elements from each of the three have been blended into one single, cohesive care planning conversation recommendation, the structure of and implementation of which have been refined in collaboration an advisory group comprising academic and clinical experts in end of life care and patient-clinician communications. It is this blended approach that offers the most compelling case for replication in the NHS in England.
- D.11 Currently, attitudes within the medical profession and a culture of targets and pressure within the healthcare system do not always support physicians and other clinicians to prioritise proactive conversations in clinic or on the ward. Experts argue that clinicians have often not been sufficiently trained to feel confident enough to initiate these conversations. However, these discussions are fundamental to effective clinical management plans. Given the increasing proportion of people living with one or more long-term conditions, it is more important than ever that we do not shy away from these conversations.
- D.12 Evidence shows that there are many potential benefits to the early introduction of end of life care and palliative care planning in a patient's treatment. These approaches can improve quality of life and wellbeing, reduce the use of aggressive care at the end of life, improve clinicians' understanding and delivery of the patient's preferences (including place of death), improve pain management towards the end of life, and reduce emergency hospital admissions. The evidence shows that these conversations not only have the potential to improve patient experiences but also lead to more effective use of resources and generate cost savings to the system as a whole.
- D.13 Improving communication about the goals of their care can enable people to participate in shared decision-making, and improve the quality of decisions jointly made to guide treatment and care.

Deliverables

Intervention

- **Care planning conversations take place in all NHS AMUs and SAUs across England**, with all admitted patients who are identified as being at increased risk of serious clinical deterioration and death during their presentation¹²⁸ and/or at risk of dying within the next 12 months¹²⁹.

¹²⁸ Using the National Early Warning Score (NEWS) 2 screening tool.

¹²⁹ Using their frailty score, the Supportive & Palliative Care Indicators Tool (SPICT) and the Gold Standards Framework (GSF).

- **A frontline clinical member of staff holds a conversation with each patient.** This trained staff member – a core medical trainee (CT2), specialist registrar (ST2), charge nurse, advanced nurse practitioner or band 6-7 physiotherapist or occupational therapist - provides medical updates, guidelines for care, and explains the care options available to the patient (including and in addition to curative care), then discusses the patients' values, treatment options and preferences with the patient and/or their family (depending on who is available and able to participate – ideally both).
- The staff member uses a planning document to capture the patient's values, priorities and treatment/care preferences. This is a live document, created during the first conversation and updated (if necessary) during subsequent conversations. Patients and their families keep a paper version for their own ongoing use/reference. Staff also record key outcomes and decisions made in their organisation's electronic system.

Critical success factors

- D.14 The studies identified several key factors affecting influencing the successful and effective implementation of care planning conversations. These include:
- Communication with the patient must occur as early and as often as possible.
 - The staff member holding conversations with patients must be able not just to give information but also to provide guidance on which interventions will be medically beneficial. The staff member must also be able to elicit patients' goals, values and preferences and have the skills to come to shared decision with the patient.
 - Patients' primary clinician will likely need support from other members of staff in conducting care planning, and to ensure this approach is embedded within the broader culture of the unit or setting.
- D.15 A culture of shared decision making and willingness to engage patients and their families in open discussions regarding their care and wishes at end of life is vital. The conversations should become embedded as 'business as usual', rather than being seen as a temporary initiative.
- D.16 Clinical staff within all AMUs and SAUs must undertake goals of care conversations to the same quality standard and capture common information fields, to ensure equal access to meaningful care planning conversations regardless of the Trust that patients are admitted to, and to enable monitoring and evaluation of the conversations.
- D.17 Trust leaders and AMU/SAU managers must be willing to release clinical staff to participate in the training and to free up capacity for clinicians to undertake the conversations on an ongoing basis. This is one of the biggest challenges to implementing the intervention, given the multiple competing demands facing acute settings. More generally, communication from the project team to the Trusts involved will be critical.
- D.18 To achieve these critical success factors, staff must understand *why* they are being asked to hold the goals of care conversations, and *what* it will mean for them and their patients on a practical basis. The benefits must be clearly articulated – to senior leaders and frontline

clinicians – including the outcomes for patients and the expected implications for service use. A programme of awareness raising and communication activities will be required, during project set up and thereafter on an ongoing basis, to emphasise the expected benefits and strength of the underpinning evidence, as well as alignment with priorities outlined in the Long Term Plan. Training would be replicated annually, to ensure new staff are familiar with the principles and processes.

Assumptions

D.19 This PID has been developed based on the following headline assumptions:

- Personalised care and shared decision making remain priorities for the NHS in England.
- Patients and their families/carers welcome the opportunity to discuss their goals of care, and can participate meaningfully in personalised care planning conversations.
- To hold personalised care planning conversations, clinicians require training/briefings regarding goals of care conversations and the underpinning principles of personalised care for patients at risk of dying within the next 12 months.
- Up to five years' worth of funding is available from NHS England & NHS Improvement to finance the project.
- The evidence regarding the benefits experienced in the reviewed studies is broadly transferable to AMUs and SAUs in England (with reductions made to the scale of the expected benefits to account for optimism bias).
- NHS Trusts across England will act as rational economic actors, and be willing to engage with the briefings, training, implementation and monitoring activities.
- All AMUs and SAUs in England will engage in the intervention fully with all eligible patients.
- Trusts already have their own care planning documents/templates in place, with no additional costs to be incurred regarding establishment or design of these.
- The End of Life Care Board will be willing to oversee the project's own board.
- Any costs incurred by other partners across health and social care (for example, community care, adult social care or informal carers) will be less than the savings generated by this intervention.
- A project team, development group, train the trainers team and faculty can all be recruited within the set-up phase of the project, with the necessary skills and experience.
- The set up, design, piloting and recruitment phase takes place during the 2020/21 financial year with a view to briefings and training involving AMUs and SAUs ('roll-out/implementation') commencing in 2021-22.

- Following successful evaluation of phase one, phase two will be launched, following the same design and implementation model.

Implementation plan

Project set up, development group formation and faculty development (months 1-10)

- D.20 Orford et al, 2017 demonstrated the necessity for staff training and detailed the training required to enable delivery of the intervention. By adapting the content of this course (iValidate¹³⁰) for an NHS context, the advisory group supporting this review has advocated developing a training programme that should be attended by AMU/SAU staff who would be responsible for holding goals of care conversations.
- D.21 One of the three documents cited above (Orford et al, 2017) clearly demonstrated the necessity for staff training and detailed the training required to enable delivery of the intervention. By adapting the content of this course (iValidate¹³¹) for an NHS context, the advisory group supporting this review has advocated developing a training programme that should be attended by AMU/SAU staff who would be responsible for holding goals of care conversations.
- D.22 It will be vital to establish a ‘development group’ to more fully design the clinical and pedagogical details of the recommended intervention, plus a ‘train the trainers’ team with appropriate skills and expertise to design the training programme in detail, with specific skills and inputs including:
- Clinical expertise and knowledge regarding end of life care and AMUs/SAUs.
 - Communication skills training expertise, including specifically engagement with vulnerable people and personalised care planning.
 - Educational skills, with a focus on workforce development in secondary care.
 - Evaluation expertise, including capturing data and insights from patients and secondary care settings.
- D.23 The train the trainers team has a key role in designing this training for Trusts and ensuring the accompanying train the trainers programme is well aligned and appropriate. It will also create a faculty of trainers and simulated patients. Developing this faculty will involve a number of key steps, including:
- Developing a ‘train the trainers’ programme
 - Identifying and recruiting a team for developing and overseeing a “train the trainers” programme: a small, high quality group of relevant experts with the necessary time and enthusiasm to develop and deliver the ‘train the trainer’ programme.

¹³⁰ More information on the iValidate education programme can be found [here](#).

¹³¹ [Idem](#).

- Work by this 'train the trainers' team to oversee the design and implementation of the 'train the trainers' programme, through which the trainers who will deliver the training and briefings in Trusts will be trained
- The train the trainers programme must be based on the two-day training and 0.5 day follow up (and 2-hour briefings) planned for Trusts, to ensure alignment
- Undertaking a pilot of the train the trainers programme.
- Recruiting to and developing a faculty of trainers with the capacity and skills needed to deliver the training programme to the Trusts
 - recruiting sufficient numbers of trainers capable of delivering communication training to clinicians in the Trusts and the establishment of how many courses each trainer will be available to facilitate on average per year
 - establishing a system for accrediting trained trainers, with annual/bi-annual updates of the accreditation.
- Recruiting to, developing and training a faculty of simulated patients, specifically trained in this aims, objectives and simulated patient roles for this programme
 - simulated patients will need sufficient capacity and relevant experience to enable them to role-play during training delivered to Trusts and be trained to improvise and provide effective constructive feedback.
- Overseeing proof of concept of the two-day modular Trust training programme.
- Developing a community of practice of the trainers who will deliver the training to Trusts. We recommend that a virtual community of practice be formed, to enable trainers to engage directly with one another after attending the train the trainers session(s). This is likely to offer benefits to trainers by way of peer support. A Google Group or WhatsApp group might work well for this function.
- Supporting initial communications and engagement with local and national stakeholders, which will subsequently be led by the project director longer term once they become established in the role. This will involve informing the design of a brochure and communication materials for use with local leaders and clinical leads in order to gain buy-in to the project, including setting out the intervention's purpose and expected benefits, including financial returns expected for Trusts and the time commitment required.
 - It is anticipated that interested parties to be targeted with communication and awareness raising materials regarding the project will include, as a minimum, all Trust medical education departments, Sustainability and Transformation Partnerships / ICSs and Strategic Clinical Networks at local and regional levels, as well as Health Education England and relevant Royal Colleges at a national level.

- D.24 Finally, there is likely to be an ongoing role for the development group in providing expert advice and critical challenge throughout the project.

Proof-of-concept work

- D.25 This report proposes that initial proof-of-concept work is then undertaken to test this intervention in a real-world setting. This work has been costed to commence and be completed during the 2020/21 financial year, following establishment of the development group and recruitment/training of an initial training faculty.
- D.26 NHS England & NHS Improvement should first identify a Trust willing to act as a 'demonstrator', implementing goals of care conversations locally to generate the proof-of-concept.
- D.27 NHS England & NHS Improvement would then closely monitor and evaluate progress and outcomes/impacts of proof-of-concept work at the demonstrator Trust. This evaluation would produce conclusive evidence that the approach set out in this report works in a present-day NHS context (evidence that could then be used to help secure buy-in from other Trusts during subsequent years), as well as learning on the practical steps that need taking to make this intervention operational and deliverable within a secondary care setting.
- D.28 Alongside this, work should be undertaken with stakeholders to more precisely model the implications of patients who receive the intervention spending fewer days in hospital, include the full impacts on Trust service utilisation, cost bases and income. This modelling would feed into both evaluation of the proof-of-concept work and subsequent evaluation throughout the lifetime of the national rollout.
- D.29 A reasonable proof of concept process might involve six months of delivery of conversations, with a further 12 months allowed for all patients involved in the trial to fully realise the anticipated benefits from their receipt of the intervention. Assuming a start date October 2020 this proof-of-concept work could therefore be completed by March 2021, with the final benefits being observed among patients in the proof-of-concept cohort by March 2022 (12 months following the last patient's receipt of the intervention).

Staff training

- D.30 Staff undertaking the goals of care conversations would need training to identify patient values, to listen to patient preferences, and to provide advice to high-risk patients accessing acute care. The content of the course would need to be agreed and developed by the train the trainers team; based on the evidence from the published studies and advisory group inputs, anticipated core content of this **training course**¹³² include:
- Learner-centred approaches exploring participants' prior knowledge, confidence and needs in undertaking personalised care goal discussions with patients approaching end of life.

¹³² The content designed and the facilitators trained by the train the trainers team, via the process detailed earlier in this recommendation.

- Frameworks both for values-driven end of life care conversations and for effective clinical communication (including the Calgary-Cambridge guide and Harvard Serious Illness guide).
- Guidance on identifying patients at risk of dying over the subsequent twelve months, including use of individual frailty scores, the Supportive & Palliative Care Indicators Tool and the Gold Standards Framework.
- Establishing whether a patient has had a goals of care conversation, during routine patient care handovers.
- Ensuring the timeliness of goals of care conversations, and how to create opportunities to initiate the conversation using appropriate communication skills.
- Key underlying patient-centered communication skills, of gathering information about goals, fears and worries, critical abilities, trade-offs, and family circumstances and wishes. These would include agenda setting, assessing illness understanding, rapport building, signposting, listening, reflective questioning, silence, and empathy.
- Looking for and responding to cues from the patient (and family/carers as appropriate).
- Presenting and discussing options with the patient and developing consensus (utilising explanation and planning communication skills including chunking and checking, patient restatement, exploring patient preferences, shared decision-making).
- Concluding, summarising and documenting about goals of care agreed¹³³.

D.31 Staff would also need sufficient training in **end of life care**, including the different curative and palliative care options available to patients.

D.32 Training on the principles and processes of undertaking personalised care planning would need to be given to the clinical staff that would have these conversations with patients about their preferences. One of the studies in this review¹³⁴ included a 2-day training workshop to prepare staff to deliver personalised care planning, and this aligns with the broader evidence regarding the efficacy of communication skills training. This review's advisory group has recommended that this approach be replicated within the NHS in England. The advisory group recommended that the training programme could be delivered in a modular form, with the modules comprising two days to complete in total. This would be followed by a half-day refresher training session several months later.

D.33 Consultants and matrons on AMU/SAU rotas would need an introductory session to understand the need for this intervention and how to listen to and act on the information other staff gather through goals of care conversations. Based on advice from this study's advisory group, this session could likely be delivered in two hours.

¹³³ These topics are identified either in the Orford et al study and/or on the advice of this study's advisory group.

¹³⁴ Orford et al, 2017.

Delivery of conversations

- D.34 The training would be targeted at key AMU/SAU staff chosen to undertake these care planning conversations with patients: core medical trainees (CT2s), specialist registrars (ST2s), charge nurses, advanced nurse practitioners and band 6-7 physiotherapists and occupational therapists.
- D.35 The goals of care conversations take place and are documented within 48 hours of patients presenting at AMUs/SAUs.
- D.36 Two consultations (on top of business as usual activity), take place, each of up to 30 minutes.

Data capture

- D.37 Information recorded by clinical staff undertaking care planning conversations at each Trust would need to serve two purposes:
- Capture a record of patients' values, priorities and treatment preferences, to inform future treatment and care.
 - Generate sufficient data to meet national monitoring and evaluation requirements.
- D.38 To ensure sufficient information is captured to meet both of these purposes we suggest that trainers work with staff at each Trust they deliver training at, to ensure that their existing processes and documentation are fit for purpose and to identify any changes/additions that need making if not.
- D.39 Trainers would, in advance of delivering their first training session to staff from any one AMU or SAU, spend time familiarizing themselves with the care planning document(s) and record keeping systems in use within that unit. If a unit's existing care planning documents and/or record-keeping systems do not capture information needed to meet both the purposes set out above¹³⁵, trainers would log this with the national project management team and liaise with key individuals at each Trust to ensure any necessary data fields are added. The necessary changes could then also be raised and discussed during briefings with senior staff and training sessions with staff who will be undertaking conversations with patients. We have suggested 0.25 days of a trainer's time to review each unit's existing processes and documents.
- D.40 For monitoring and evaluation purposes, all relevant data would need to be submitted to the national project management and evaluation teams. Collation, standardisation and submission of this data would need to be undertaken by a member of administrative staff located at each Trust. We are proposing that this would require 0.25 FTE input from an administrative staff member at each unit.
- D.41 While Trusts' existing planning documents and record keeping systems should all be capable of capturing the level and detail of information required for both care planning and monitoring/evaluation purposes, we recommend that options for national standardisation of planning documents and data are explored as implementation progresses. This will be

¹³⁵ Such information including evidence of a patient's values, treatment preferences (such as preferred place of death) or core clinical outcomes (e.g. length of stay in hospital, incidence of re-admission).

particularly important is care planning documents vary significantly in their content and coverage.

Management and oversight

D.42 The project will be owned, managed and overseen by NHS England & NHS Improvement.

Project management team

D.43 A team of posts is recommended by the advisory group as being essential to centrally manage and perform the various tasks associated national rollout and implementation of this intervention. The costings assume that these are new, additional posts, based within NHS England & NHS Improvement.

D.44 The roles of the project management team would include:

- Supporting and liaising with the Faculty regarding training programme design and trainer/simulated patient recruitment, to ensure this remains on track and appropriate.
- Development of training materials.
- Procuring and sharing promotional materials.
- Organising pilot train the trainer sessions; collating and sharing feedback from the pilots, and liaising with the Faculty to ensure revisions are undertaken as appropriate.
- Extensive liaison with all 152 Trusts across England, to secure interest and buy in to the training and intervention, raising awareness amongst clinicians and leaders, responding to any queries and noting any concerns/barriers raised.
- Booking training sessions and liaising with trainers/simulated patients to ensure training take place in line with Trust availability.
- Monitoring delivery/attendance of training, and the subsequent holding of goals of care conversations and documenting of goals.
- Liaison with other national stakeholders.
- Risk management and monitoring, budget management and reporting progress to governance board,
- Oversight of the independent evaluation, including working with the Faculty to devise the evaluation specification, liaising with NHS England's procurement team to commission the evaluation, and contract management of the evaluators.

Governance and oversight

D.45 Dedicated governance would be needed to oversee national rollout of this intervention, including monitoring the rollout and delivery of training, and the implementation of goals of care conversations with patients.

- D.46 The most appropriate body for overseeing this work would be a dedicated project board, formed specifically for the purpose of overseeing this project. We recommend that this includes development group members, as well as the NHS England & NHS Improvement Strategic Lead for the project, and the Project Director (once appointed), with secretariat provided by support staff within the project management team.
- D.47 This group should report into the existing NHS England & NHS Improvement End of Life Care Programme Board, providing six monthly or quarterly updates on progress, as appropriate.
- D.48 Specific terms of reference will be required for the Board; to be drafted as soon as possible following project inception, led by development group members and the Strategic Lead for the project.

Recommended monitoring and evaluation arrangements

- D.49 Routine monitoring regarding the roll-out and implementation are vital for any programme of this scale and nature. In addition, independent evaluation of the intervention during the four years of its duration will be crucial, to ensure that learning is generated and shared regarding good practice and effective implementation (to feed back to policy makers and acute care providers) as well as pitfalls to avoid and key enablers for success. Monitoring and evaluation are also vital to evidence the extent to which anticipated outcomes and impacts are realised, and any knock-on implications elsewhere in the health and social care system, or for patients and/or their families, including any unanticipated and/or negative outcomes that may emerge.

Monitoring of training implementation (progress)

- D.50 Monitoring needs to happen at a national level. Initially, monitoring is vital regarding the achievement of key milestones during the set-up phase of the programme. Specific monitoring activities that we recommend are below, alongside suggested leads and metrics.

Table D-1: Recommended minimum monitoring activities to be undertaken during the scoping and design phase

| Monitoring area/focus | Metrics | Suggested lead |
|--------------------------------|---|---|
| Project team recruited | Recruitment materials developed and publicised Recruitment interviews held and candidates appointed Staffing levels in the project team | NHS England & NHS Improvement Project Director/lead |
| Trainers recruited and trained | Number of applicants to become trainers Number of trainers recruited Number of sessions booked and delivered to train the trainers Attendance at train the trainer sessions (e.g. to ensure 100% training of trainers) Expected reach of each trainer | Faculty leads Project Director |
| Feedback from trainer sessions | Short self-completion survey post-training Explore confidence, knowledge development and general reflections on the utility and | Faculty leads Project Director |

| Monitoring area/focus | Metrics | Suggested lead |
|--|---|---|
| | relevance of the training, as well as any further support needs / barriers to implementation of the learning | |
| Promotional and awareness raising activity regarding the programme | Number of communication materials produced Number of emails sent to Trusts Social media monitoring Enquiries received by the programme team | Project Director |
| Trusts and clinicians booked to receive training | Number of bookings – nationally, by region, and by Trust, as well as by type (AMU/SAU) Numbers of sessions booked relative to AMU/SAU staffing levels in each Trust | Project Director |
| Pilot training feedback | Short self-completion survey, undertaken pre- and post- training, exploring confidence, knowledge and willingness to undertake goals of care conversations with patients approaching end of life, as well as feedback regarding the quality of the training | Designed by Faculty Implemented by Trainers Collated by Project Coordinator |
| Programme and tool design progress and completion against milestones | Milestones log Action plan Monthly monitoring | Project Director |

Source: SQW

- D.51 During the main phase of training roll-out (post-scoping), we recommend that the following monitoring information be captured and reviewed, to ensure progress continues as planned, and to identify any emerging slippage or issues.

Table D-2: Recommended minimum monitoring activities regarding the training, to be undertaken during the main implementation phase

| Monitoring area/focus | Metrics | Suggested lead |
|--|---|---|
| Take up of the training | Number of training sessions delivered – nationally, by Trust, by unit and by grade, compared to AMU/SAU staffing levels, and compared to roll-out plan | Project Director |
| Trust engagement (and reasons for any disengagement) | Feedback from Trusts/units unwilling to participate in the training | Project Director |
| Feedback regarding the training | Short self-completion survey, undertaken pre- and post- training, exploring confidence, knowledge and willingness to undertake goals of care conversations with patients approaching end of life, as well as feedback regarding the quality of the training | Designed by Faculty Implemented by Trainers Collated by Project Coordinator |
| Trainer capacity | Number of training sessions delivered per trainer, compared to expectations and their capacity | Project Director |

Source: SQW

- D.52 Underpinning the monitoring plan requires early development of a detailed project plan with key dated milestones and leads identified for each phase. The development group, working

alongside key NHS England & NHS Improvement leads, would be well placed to undertake this role.

Monitoring of intervention implementation (goals of care conversations)

- D.53 Suitable monitoring metrics must be devised in collaboration between the development group and governing body. The table below sets out the recommended minimum monitoring data to be collected regarding the implementation of the intervention.

Table D-3: Recommended minimum monitoring activities regarding the training, to be undertaken regarding implementation of the intervention within Trusts

| Monitoring area/focus | Metrics | Suggested lead |
|---|--|--|
| Goals of care conversations implementation | Numbers of conversations held, numbers with each patient, who conducted the conversation, by Trust and department/ward Demographic data regarding patients in receipt of the intervention | Data provided by Trust analysts monthly; collated and analysed by the project team |
| Non-implementation rates | Numbers of patients eligible but decision taken not to undertake a goals of care conversation, nationally, by Trust and unit, with reasons noted | |
| Patient refusals | Numbers of patients declining conversations (with reasons noted where provided) | |
| Documentation of patient goals | Numbers of care plans developed, number of plans per patient | |
| Patient goals, including a patient's preferred place of death and treatment preferences | Tick-box monitoring data, captured by Trust, unit and patient condition/demographics | |
| Plan dissemination | Tick-box monitoring data regarding which roles/organisation each plan has been shared with (for example, primary / community or social care, or other acute units) Patient/carer access to their plan | |
| Conversation monitoring | How long each conversation took; who conducted the conversation; date of completion; time since admission to the unit | |

Source: SQW

- D.54 These monitoring metrics are to be agreed by end of the proof of concept year, 2020/21.
- D.55 Monitoring data should be uploaded by staff electronically by completion of a standardised template (we recommend the information be captured monthly, and returned directly to NHS England), as this both greatly reduces the administrative burden of data collection and submission, as well as ensuring data entered by staff is entered in a consistent format. Monthly returns will enable missing or incomplete responses to be quickly identified and mitigation put in place.

Measuring outcomes and impacts

- D.56 Measuring the impact of the intervention will be important for understanding the full extent of the benefits realised by patients, by taxpayers and by the healthcare system once this intervention is in place.

D.57 Number of days spent in hospital following receipt of a goals of care conversation is a key impact measure that should be explored in any evaluation work.

D.58 In addition, there are further potential impacts that studies in this area have explored that would also be worth examining. These are presented in the table below.

Table D-4: Recommended outcomes monitoring approach

| Impact / outcome area | Indicator/metric | Method/tool | Suggested lead |
|-------------------------------------|--|--|--|
| Staff experience | Staff confidence and willingness to engage patients and families/carers in conversations about end of life care and place of death | Pre- and post- training survey tool | Project Director; survey issued and collated by trainers at the start of the first and end of the second days of training |
| | Staff capacity to undertake the conversations and associated monitoring | Qualitative feedback from staff | Trust analysts to provide monthly data on barriers to implementation and conversations; evaluators to capture qualitative experience insights from staff |
| | Impacts on staff morale | Trust monthly monitoring returns | |
| Patient and family/carer experience | Patient and family/carer experience of care | Friends and Family Test data | Evaluators to capture survey and qualitative data |
| | Patient and family/carer sense of control over decisions regarding their care | Patient experience surveys | |
| | Patient and family/carer wellbeing and quality of life | Qualitative feedback from patients and carers/families | |
| | Patient and family/carer feel that they 'own' their care plan | | |
| | Patient and family/carer feel they have enough information to meaningful engage | | |
| Service use and clinical outcomes | Emergency readmissions within 30 days of discharge | CCG Outcomes Indicator Set | Project Director |
| | Intensive care admissions not resulting in discharge from the unit | Trust monitoring monthly returns | |
| | Patients' actual place of death (to contrast with the preferred place of death recorded in their plan). | To be determined by the evaluator and project board | |

Source: SQW

D.59 It will be vital to also track patients' use of care services following receipt of a goals of care conversation, to examine whether any reductions in hospital-based care are being offset by increased uptake of other services, which may include adult social care, community care, primary care and/or informal care.

- D.60 Consideration should also be given to the establishment of a **comparator group**. A phased rollout would enable the same outcome and experience metrics listed above to be collected from a non-intervention cohort of patients in later implementer sites who are of a similar profile (age, sex, existing health condition(s), close of end of life etc.) to those receiving goals of care conversations. Differences between the intervention group and this comparator group could then be observed.

Formative evaluation

- D.61 Alongside monitoring information, it will be critical to explore the qualitative impacts and learning emerging regarding the intervention. For example, formative and process learning regarding the effectiveness of its design and implementation, including:
- Identifying any pre-conditions or critical success factors for effective implementation and outcomes realisation, and any key contextual factors, at local and national levels.
 - Capturing details of challenges, how these have been overcome, and any barriers to effective implementation and outcomes realisation.
 - Staff experience of the training, conversations and monitoring.
 - Reflections on the training and conversation tools and their utility.
 - Any suggested improvements, and aspects working particularly well.
- D.62 This feedback could be captured via focus groups or in-depth discussions/interviews with a sample of clinicians involved in implementing the conversations, as well as with trainers and the programme manager/coordinator. We recommend capturing this feedback and reporting at a mid-point in the process, to inform refinement of the approach.

Phasing during years 2 and 3

- D.63 The project costs assume Trusts are trained at equal numbers throughout the year, e.g. 12-13 Trusts receive the two-day training and two-hour briefings per month.

Key risks, issues and mitigation strategies

- D.64 Careful, thorough and regular risk management will be key, given the scale of roll-out and engagement planned. The table below presents an overview of anticipated potential risks and issues, alongside proposed mitigation strategies. This has been developed based on the studies identified in the evidence review, as well as our knowledge of other personalised care planning interventions.
- D.65 One of the most significant risks concerns the engagement and buy-in of Trusts to the intervention and training requirements. This is vital to successful rollout and implementation of the intervention, and this paper has been developed on the assumption that Trusts will act as rational economic actors. Mitigation strategies regarding this are outlined below; we recommend that this remains at the forefront of NHS England & NHS Improvement and faculty planning activity, to ensure all possible steps are taken to militate against this risk emerging as an issue.

Table D-1: Risks and mitigation

| Risk/issue | Likelihood (1-5) | Impact (1-5) | Proposed mitigation |
|---|-------------------------|---------------------|---|
| Resistance from clinicians and Trusts | | | |
| Trusts unwilling to sign up to implementing the intervention | 4-5 | 5 | Emphasise the benefits expected (for Trusts, as well as patients), including the financial case underpinning the recommended intervention, and highlighting how the approach aligns with the requirements set out in the Long Term Plan. Wide-ranging communication activities and engagement planned with all 152 Trusts, to secure clinical and leadership buy in, and overcome any concerns raised. |
| Busy clinicians unwilling or unable to attend the training | 4-5 | 4 | Start with piloting in willing sites; capture and disseminate 'quick wins' to encourage others. Co-production where possible with a sample of staff to ensure plans are pragmatic |
| Initiative fatigue limits buy in and/or implementation; workforce scepticism | 3-4 | 3 | Present as the new business as usual approach; emphasise national roll-out |
| Challenges regarding implementation | | | |
| Inconsistent implementation | 4 | 3 | Clear guidance and standard forms for completion; quality audits |
| Turnover amongst the (trained) workforce; reliance on locums limits consistent implementation | 4 | 3 | Refresher training. Consider building training into routine training for relevant clinician roles |
| Variable quality and coverage of Trust care planning documents, risking variable recording and implementation | 3 | 3 | Training to focus on the core elements of effective goals of care planning. Core elements to be included in all care plans to be agreed by the development group. Discussion between trainers and Trust unit managers to ensure existing care plans are used to inform the training delivered to staff. Monitoring returns will seek core data from all Trusts; resources for Trust and national level data management time built into project costings |
| Goals of care conversations take longer than anticipated | 2 | 4 | Standardised approach and form(s), approach designed for use with frail, elderly and ill patients, incorporating admin time |
| Patient and family engagement and experiences | | | |
| Some patients are unable to meaningfully engage or become distressed discussing end of life care goals | 2 | 4 | Sensitive approach explored during training. Support to enable patients with additional needs to meaningfully participate (e.g. Easy Read versions of DMTs). |
| Family resistance to the decisions or approach taken | 2 | 3 | Family engagement where relevant/possible; emphasise that the approach is about empowering the patient and respecting their wishes |

| Risk/issue | Likelihood (1-5) | Impact (1-5) | Proposed mitigation |
|--|-------------------------|---------------------|---|
| Outcomes realisation | | | |
| Unable to meet patient goals | 2 | 5 | Realistic discussion of what services and support are available with the patient, as well as their needs and goals. Conversations to be revisited as needed |
| Number of conversations undertaken does not align with expectations | 4 | 5 | Monthly monitoring to identify areas not undertaking expected numbers of conversations, to explore reasons why; use findings to inform refinement/support as needed |
| Patient bed days and use of care services do not reduce as expected | 2 | 5 | Monthly monitoring; formal evaluation and review; capture learning as to 'why not' |
| Knock on increases in demand elsewhere in the system | 4 | 4 | The knock-on implications are not explored in the study, so this remains an as yet unquantifiable risk. Monitoring service use amongst a sample of patients may help to identify any emerging issues. |
| Phase two rollout based on less conclusive evidence base (e.g. evidence comes from different types of settings); risks outcomes not meeting expectations | 3-4 | 4 | Optimism bias built into the model; monthly monitoring and learning from phase one. |

Source: SQW

- D.66 Monitoring and mitigation of risk would be managed via the same levers as quality management. The project team would routinely (monthly, with exception reporting as needed) monitor risks. The project team would escalate any that exceed project tolerances or threaten project delivery to the dedicated governance board.