



**Building
on the best**

**Building on the Best
in Scottish Acute Hospitals**

Evaluation Report
(December 2018)

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Building on the best

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About this report

This document is a final report on the Scottish arm of the UK-wide quality improvement programme *Building on the Best*. It describes the background and local context of this work and outlines its implementation and key learning.

In Scotland, *Building on the Best* started in October 2016 and was completed in September 2018.

The achievements of the project resulted from the commitment and collaborative spirit of the Steering Group, Site Leads and Ward Staff, with the support of the SPPC Team (with particular thanks to Dr Barbara Kimbell, Project Manager).

EXECUTIVE SUMMARY

The Need for Action

At any point nearly 1 in 3 hospital beds in Scotland is occupied by someone who will die within 12 months. Hospital admissions increase towards the end of life and many people are admitted to hospital on an unplanned basis with deteriorating health and uncertain outcome. There is a need to refine processes and to support staff to deal with this large and often complex area of work. There is also a need to prepare and support individuals and their families to cope with the hospital experience.

What this Project Did

As part of a 2-year UK-wide programme funded by Macmillan Cancer Support a project manager was employed by Scottish Partnership for Palliative Care. She worked with ward staff in 3 Scottish acute hospitals with the aim of improving the experiences of individuals and their families. The project manager sought input from individuals in hospital, their relatives and the public, as well as staff. At ward level the work was informed and supported by local palliative medicine leads, but was led by staff of other specialities.

An initial scoping phase of observation and interviews was conducted, primarily with staff, but also with individuals and their families. The results formed a basis for wards to reflect on, discuss and plan to test changes to existing practices. Evaluation was primarily via qualitative interviews.

Results

A variety of changes were prompted and tested.

Five prompt cards were developed and tested across multiple wards. These were designed to be used as a quick reference tool to support staff with the identification of patients who might benefit from a palliative care approach as well as to guide them in effective approaches to conversations about deteriorating health and anticipatory care planning with individuals and family members. An evidence-based core communication mnemonic (RED-MAP) was used. The cards were sized to fit into the back of the standard ID card used by NHS Scotland staff. A linked poster for the public was displayed in wards.

Interventions to develop communication skills and confidence were prioritised by some ward teams, particularly for medical staff and healthcare assistants.

Some ward processes were changed, to improve intra-team communication.

Conclusions and Learning

The scoping phase generated rich learning and was an effective catalyst for change.

The engagement and commitment of ward staff was strong. However, workforce pressures and competing priorities meant that progress was slow and uneven.

Measuring impact was difficult because of time pressures and also methodologically.

Signs of cultural change were noted. Such changes are very significant.

Some of the qualitative feedback suggests positive impacts on the experiences of individuals and their families were achieved.

There is enthusiasm for continuing and developing the work beyond the first phase of the project.

SECTION 1: BACKGROUND

1.1 Project origin

In 2015, Macmillan Cancer Support identified improvements in palliative and end-of-life care (PEoLC) in acute hospitals as a priority area. They supported this with a UK-wide quality improvement programme, *Building on the Best*. In England, Macmillan worked closely with the National Council for Palliative Care (now Hospice UK). In Scotland, the programme was delivered in partnership with the Scottish Partnership for Palliative Care (SPPC).

Building on the Best was based on a detailed scoping review of UK policies and best practice guidance, research evidence and public-patient involvement work. It aimed to:

- Focus on 'acute hospital care' while recognising that this setting is part of a wider system of health and social care.
- Be collaborative within participating hospitals and across the programme in each nation and the UK as a whole.
- Complement and build on existing quality improvement initiatives, education programmes and other developments that support integrated PEoLC in acute hospitals.
- Foster local ownership, active participation and leadership by multi-disciplinary clinical teams, local improvement teams and management.
- Use a range of evidence-based methodologies to improve care, measure outcomes and demonstrate positive impacts on the experiences of patients, family members and staff.
- Share experiences, learning, outcomes and evaluation throughout the programme across the UK.

A consensus workshop identified four priority areas for the programme:

- Shared decision-making about treatment and care
- Effective handovers (within hospitals and between hospital and community)
- Pain and symptom management
- Proactive care planning in outpatient clinics

The well-documented challenges associated with delivering high-quality, person-centred PEoLC in the acute setting were addressed in diverse hospitals and within the varied policy environments of the UK's nations. The programme launched in England in March 2016 and in Scotland in October 2016. Importantly, while funded by Macmillan Cancer Support, *Building on the Best* did not solely focus on the needs of cancer patients, but on people approaching the end of life with any condition.

1.2 Local project context

For Scotland, two of the *Building on the Best* topic areas had a particularly good strategic fit with existing work locally: effective shared decision-making and improved communication between primary and secondary care. Consequently, the project in Scotland specifically sought to improve shared decision-making (SDM) and information-sharing in the acute medical setting for people with deteriorating advanced disease and their families.

The local approach planned to integrate two key aspects of quality improvement in relation to care planning and communication with people whose health is deteriorating and their families:

- A structured approach to communication and information-sharing by hospital teams.
- Collaborative work with patients, families and support groups to develop patient information resources to support active participation in care planning conversations.

1.3 Project structure

1.3.1 Project management and governance

A project steering group of key stakeholders regularly reviewed progress and emerging findings. Clinical input to the group was provided by a lead Palliative Medicine clinician from each of the participating hospitals, a Nurse Consultant and an academic General Practitioner. Representation from Health Improvement Scotland and the National Clinical Lead for PEO LC and Nursing ensured alignment of the project with national policy. Representatives from Macmillan Cancer Support advised on patient and public engagement and communications. A Project Manager based at the SPPC led the day-to-day running of the project, undertook the initial patient and public involvement (PPI) component of the project and provided direct support to the participating sites. Progress reports were provided monthly to the Macmillan Regional Team in Scotland, Macmillan UK HQ and the UK-wide *Building on the Best* operational group, and quarterly to the Macmillan UK programme oversight board.

1.3.2 Project sites

Three Scottish acute hospitals participated in the programme. These sites were selected on the basis of their established programmes of teaching and development to support improvements in palliative care and their existing strong links with other local palliative care services and community support services. Specifically, the project involved the Acute Medicine wards, which admit a high proportion of patients with deteriorating health and complex needs due to multi-morbidity, and one medical speciality, gastroenterology. Advanced liver disease is the third commonest cause of premature death in the UK and its incidence is rising rapidly. This group of patients are younger than people with other types of organ failure and anticipatory care planning is particularly challenging because of the uncertainty of the illness trajectory and the acute nature of the complications experienced by these people. Most gastroenterology wards care for people with advanced liver disease alongside people with cancer and so provide a setting where the different challenges of future care planning with these groups can be evaluated and compared.

The following provides contextual information about each of the participating hospital sites as well as some relevant local baseline information:

Hospital Site A

Site A is a teaching hospital and cancer centre with around 900 beds, including a large medical assessment unit. The hospital provides services in accident and emergency, critical care, lung and colorectal cancer, palliative care and most medical and surgical specialties. Prior to joining *Building on the Best*, the local Palliative Care Team had undertaken a small-scale audit and intervention which sought to improve the delivery of palliative care in its Acute Medical Unit (AMU) through a daily proactive visit by the hospital Palliative Care Team to the AMU to review and discuss patients who may benefit from a palliative care approach. The intervention was extremely positively received by the AMU staff and resulted in quicker holistic palliative care reviews, quicker transfers to an appropriate place of care and fewer inpatient days in the acute hospital setting.

Hospital Site B

Site B is a teaching hospital and tertiary referral centre with around 1000 beds for a wide range of medical and surgical specialties. The acute medicine team has close working relationships with the hospital palliative care team and had previously undertaken several collaborative audits and a research study of patients admitted with deteriorating health to the acute medical admissions unit and the two general medicine wards. The hospital Palliative Care Team visit these ward areas daily to discuss or review any patients identified by the ward staff as needing palliative care. The gastroenterology unit admits people with cancer and many with advanced liver disease as part of the wider hepatobiliary and transplant service in the hospital. The inpatient ward had recently completed a research study looking at proactive supportive care from a liver nurse specialist trained in palliative care for people with advanced liver disease.

Hospital Site C

Site C is a large district general hospital with around 760 beds. This hospital provides emergency medicine, general medical and surgical services and has close links with the regional cancer centre. Shortly before joining this project, a postal questionnaire was administered to all doctors at site C working in inpatient medical and surgical specialities, emergency medicine, anaesthetics and intensive care medicine. The survey explored and compared the experiences of both consultants and lower-grade doctors with respect to caring for dying patients in an acute hospital setting, and examined how these experiences related to existing training and learning opportunities and support offered to doctors.

1.3.3 Project approach, timeline and overview

Although the project had identified 2 themes for focus, it was important to adopt a participative approach which supported ward staff to identify areas of priority for change. In Scotland, the project started in October 2016, running for 2 years to September 2018. In order to maximise cumulative learning generated across all participating sites and to support activities at each location, site involvement was staggered – initial work started at site A, followed by site B and finally site C. However, throughout the lifetime of the project all three sites contributed to its ongoing development and related activities through involvement in the project steering group.

The following outlines the broad phasing of planned activities along the project timeline:

Development phase (October 2016 – March 2017)

- Establishment of relationships with key stakeholders nationally and at each of the participating hospital sites.
- Completion of R&D, Caldicott Guardian, health service evaluation approvals and other hospital senior management team processes for the proposed project in line with the requirements in each participating NHS health board and hospital site.
- Development of draft resources and approaches to support holistic assessment, communication and anticipatory care planning with people whose health is deteriorating.

Scoping phase (April 2017 – December 2017)

- Scoping of current practice in participating wards at sites A and B.
- Patient and public consultations to inform project and resource development.
- Development of quality improvement plans in each locality.

Implementation phase (January 2018 – June 2018)

- Testing and refinement of draft resources at sites A, B and C.
- Implementation of any other QI activities informed by local scoping findings.
- Local evaluations using standard quality improvement methods.

Evaluation phase (July 2018 – September 2018)

- Programme evaluation with participating sites.
- Final data synthesis and reporting.
- Project dissemination (continues after completion of project).

SECTION 2: ACTIVITIES

2.1 Site activities

To establish a baseline understanding of current challenges and opportunities for improvement, we undertook in-depth scoping of current practice in the participating wards at sites A and B. Site C acted as an additional test site for the draft resources that were developed during the development phase to support the aims of the project. The implementation phase therefore featured two types of quality improvement activities in the participating wards:

1. Activities informed by the findings from the scoping of current practice. These activities were specific to the needs and priorities of the individual ward and/or site.
2. Testing of draft resources aimed at staff and patients/caregivers to support shared decision-making. These resources (**Appendix 1**) were:
 - Prompt cards for ward staff to facilitate a structured approach to communication and shared decision-making with patients and families.
 - An information leaflet and poster written for patients and families that included question prompts linked to the staff resources.

Five prompt cards were developed for testing by the ward staff during the project. These were designed to be used as a quick reference tool to support staff with the identification of patients who may benefit from a palliative care approach as well as to guide them in effective approaches to conversations about deteriorating health and anticipatory care planning with patients and family members. An evidence-based core communication mnemonic (RED-MAP) was used. The cards were sized to fit into the back of the standard ID card used by NHS Scotland staff.

- *SPICT*: This card summarised the general indicators of SPICT™ (Supportive & Palliative Care Indicators Tool) and prompted staff to identify patients with deteriorating health and start key anticipatory care planning steps.
- *ACP-Talk 1*: This card provided a structure and prompt questions to help staff initiate an early anticipatory care planning conversation.
- *ACP-Talk 2*: This card provided a structure and prompt questions to help staff open conversations with people whose health is clearly deteriorating and initiate anticipatory care planning in this context.
- *ACP-Talk 3*: This card provided a structure and prompt questions to help staff talk about dying and planning care for people who are in the last days of life with patients and families.

- CPR-Talk: This card was added later to help address the challenges associated with talking about CPR in the context of deteriorating health and dying and is designed to be used alongside ACP-Talk 3.

The patient/caregiver information leaflet and poster were designed to complement these staff resources and sought to promote awareness and preparedness for decision-making conversations during a hospital admission. The posters were intended to be displayed in strategic areas of the hospital ward to ensure maximum visibility for patients and visiting family, and included a prompt to pick up a leaflet for more detailed information.

A first draft of the resources was produced by one of the site leads during the development phase of the project. These drafts were then shared with the project steering group, other healthcare professionals and members of the public through our consultation activities outlined in section 2.2. The resources were subsequently revised in line with the comments received to create the baseline resources used for testing and further refinement on the participating wards. Macmillan Cancer Support Scotland Communications staff provided support with poster design and printing. Testing of these resources was undertaken by all three project sites.

Baseline scoping audit (Site B)

To establish an understanding of current practice and provide baseline data for *Building on the Best*, a core medical trainee (RH) conducted an audit of one patient admitted to every bed space in the two acute medicine wards over a 2-month period, giving a total of 72 patient data sets. This method was chosen because the beds are used for different types of patient. Outcomes were reviewed at 6-months. The 29 male and 43 female patients had a median age of 65 (range 20-98). 32% had multi-morbidity or general frailty, 25% advanced neurological conditions, 12% organ failure, and 6% cancer. Admission was mostly for an exacerbation or complication (54%) or an infection (32%). A Key Information Summary was available for 39% but a third of these had no anticipatory care plan (ACP). After 72 hours, 25% had a clear ACP and 18% had a DNACPR form (8% on admission) but conversations with patients and families were not well documented. Of the 54 (75%) patients discharged home, 30 had some mention of future care planning but only 2 had a clear and detailed ACP. This patient group were obvious candidates for ACP; 57% had an unplanned admission in the year before the audit, and 56% of those discharged home had a least one further admission in the next six months (range 1-9).

2.2 Patient and public involvement activities

As service user and public engagement was central to this project, we sought to work closely with PPI groups in the participating health boards. In doing so, we hoped to:

- a. Generate better understanding of people's experiences of shared decision-making in the context of an unplanned hospital admission with deteriorating health and their ideas for improvement.
- b. Work with service users and members of the public to develop information and support resources for patients and families.

We approached national and local organisations advocating for patients, caregivers or older people, generic patient/public involvement (PPI) networks as well as groups with established links to the

project team. The resultant focus groups were co-ordinated by the Project Manager and facilitated in partnership with Macmillan engagement staff. Section 3.2.4 outlines further details of these focus groups and their outcomes.

SECTION 3: LEARNING

3.1 Evaluation approach and methods

Building on the Best in Scotland sought to support hospital staff to more consistently, effectively and collaboratively conduct anticipatory care planning with patients whose health is deteriorating with limited reversibility. It also aimed to have patients and families better informed, prepared and able to contribute their views and priorities to decisions regarding their future treatment and care. To assess the success of this project in achieving these ambitions, the planned evaluation framework considered measurement approaches related to three specific aspects of project delivery:

1. Effectiveness and impact of site-specific quality improvement activities
2. Effectiveness and impact of the draft resources
3. Impact of project participation on staff and patient/caregiver experiences and outcomes

The planned local evaluation approach was developed by the project steering group. To facilitate the comparison of findings, it aimed to identify measurement approaches which were uniform across the participating sites and aligned as closely as possible with the methodologies used in the other UK nations. At the same time, the group recognised that the framework needed to be as flexible and responsive as possible to local priorities, processes and structures in order to reduce the additional burden on participating ward teams. It was recognised that this would limit the extent to which comparisons could be made across the sites.

Planned versus actual measurement

In common with most of the programme across the UK, *Building on the Best* in Scotland struggled to deliver an adequate framework of measurement. The reasons for this are explored in a section under Programme Learning below. A fairly limited level of data gathering was planned, but in the latter stages of the project it became clear that this was not going to be achieved. The following table shows the difference between planned and actual measurement. The end of project evaluation is therefore largely based on a series of independently conducted qualitative interviews (the methodology is described at Appendix 2).

1. Effectiveness and impact of site-specific quality improvement activities

The appropriate evaluation approach is informed by the activity in question and the measurement approach determined by the individual staff teams.

2. Effectiveness and impact of the draft resources

ACTIVITY	PLANNED MEASUREMENT APPROACH	MEASUREMENT IN PRACTICE as at AUGUST 2018
Communication aids for staff	<ul style="list-style-type: none">• Feedback from hospital staff on their experiences of using the prompt cards, and specifically on the cards' usefulness and the user-friendliness of the current format	<ul style="list-style-type: none">• As planned but limited quantity
Patient information leaflet and poster	<ul style="list-style-type: none">• Feedback from hospital staff regarding perceived effectiveness, impact, and resource placement• Ward staff to seek feedback from patients and families regarding resource awareness and thoughts on content and effectiveness	<ul style="list-style-type: none">• Feedback not secured on poster and information leaflet

3. Impact of project participation on staff and patient/caregiver experience and outcomes

ACTIVITY	PLANNED MEASUREMENT APPROACH	MEASUREMENT IN PRACTICE as at AUGUST 2018
Comparison against baseline data	<ul style="list-style-type: none"> • Comparison against the scoping findings at sites A and B where appropriate • Re-audit of inpatient admissions to Acute Medicine at site B • Re-run of questionnaire survey about medical staff's confidence regarding the care of dying patients at site C 	<ul style="list-style-type: none"> • Not achieved
Patient/caregiver perceptions	<ul style="list-style-type: none"> • Hospital staff to administer CollaboRATE survey tool to inpatients and their families to gain their perceptions and experiences of shared decision-making on participating wards • Review Patient Experience survey data where these exist locally 	<ul style="list-style-type: none"> • Not achieved
Staff perceptions	<ul style="list-style-type: none"> • Short telephone interviews with key staff in each participating ward as well as with site leads regarding their experiences and perceptions of changes to local attitudes, practices or processes which they feel can be attributed to project participation. 	<ul style="list-style-type: none"> • Delivered as planned

3.2 Learning at different levels and stages

This section presents the key learning generated by the *Building on the Best* project in Scotland.

The first part (3.2.1) outlines the main findings from the baseline scoping of current practice.

The second part (3.2.2) details the testing of the draft communication resources, and describes other further quality improvement activities undertaken by the staff teams in relation to this project. At the point of evaluation in August 2018, all three sites were at different stages regarding the implementation of site-specific and all-site improvement activities. Site A had successfully embedded one activity in day-to-day practice and was in

the process of implementing two further activities. Site B was in the process of implementing two improvement activities, and Site C was preparing to test out implementation activities.

The third part (3.2.3) part considers the effectiveness and impact of a programme such as *Building on the Best* in effecting engagement and change in acute hospitals with respect to current attitudes and approaches relating to the care of patients who are approaching the end of life. It also considers the process and practicalities of working closely with acute hospitals on the development, implementation and evaluation of quality improvement activities in the area of palliative and end-of-life care.

3.2.1 Learning from the baseline scoping

Given the importance of a collaborative approach to working with hospital teams and a commitment to involving service users as active participants throughout, data was collected in three ways:

- From interviews with hospital staff, patients and family caregivers;
- From routinely available documents and data about service provision and outcomes;
- Through observing care processes and interactions on the participating wards.

All data collection was undertaken by the Project Manager, an experienced health services researcher. The planned methodology for conducting the ward observations was based on the Workplace Culture Critical Analysis Tool (WCCAT). However, the logistics of observing certain ward activities, and particularly doctor-patient interactions, proved difficult in practice due to some of the wards' physical environments and modes of working. Scoping was consequently refocused to concentrate on the observation of staff discussions and decision-making regarding their inpatients' ongoing treatment and care as well as on maximising the feedback gathered through the stakeholder interviews.

Interviewing patients and caregivers proved challenging due to patients' generally poor, and often actively deteriorating, condition during inpatient episodes and in identifying the appropriate time for approaching them. We consequently also consulted the findings of local patient experience surveys, which included items relevant to shared decision-making (SDM), for each of the participating wards. As such, patient and caregiver feedback gathered during the scoping phase was relatively limited and specific to each locality. However, we elicited relevant views regarding SDM in the acute hospital setting more generally as part of our PPI activities, the findings of which are outlined in section 3.

Findings from each of the three data sources (interviews, documents/records and observations of practice) were integrated to describe the challenges and resources regarding high quality care of people with deteriorating health and their family members, and formed the basis on which the individual staff teams subsequently agreed their priorities for change. As site C acted as a test site only no local scoping was undertaken. The following scoping data were collected at sites A and B:

- 60 episodes (77 hours) of observations of general ward activities, ward rounds, multi-disciplinary staff meetings, handovers, individual doctor-patient/caregiver interactions
- 44 interviews with ward staff (involving all levels of nursing and medical staff)
- 8 interviews with patients and family members
- Findings of local inpatient experience surveys for each participating ward
- Current use of documentation and leaflets
- Case note review of 72 inpatients (site B only) – see Section 2.1 above.

The following summarises the findings that were common across the participating sites. Where suitable, these findings are illustrated using quotes from the qualitative interviews.

- 1. There is currently no systematic identification of people who may benefit from anticipatory care planning, e.g. through the use of a validated tool such as SPICT™.**

There is always that question about are we being realistic, especially with the chronic patients. We do set reasonable long-term goals with them themselves, but on two occasions I've seen people who are unwell here and I do think, "You're going to be ill a couple of weeks and then you're going to run out of steam." When are we going to recognise when is that point? I think we could maybe be better at recognising that.
(Specialty Trainee)

- 2. Levels of staff expertise and confidence regarding discussing deteriorating health with patients and families vary greatly, but there is enthusiasm for learning and improvement by all ward staff, including experienced consultants.**

Some sort of communication skills course specifically for breaking bad news and about resuscitation would be great.
(Acute Medicine Consultant)

If they want me to do advanced communication training then that would be great, I would love to do something like that.
(Specialty Trainee)

You always want to learn. And if there's new techniques out there or another way of doing things then I would be quite willing to do that.
(Acute Medicine Healthcare Assistant)

3. Anticipatory care planning conversations with patients and families are typically conducted by senior staff, with only occasional involvement by junior doctors and nursing staff.

Personally I would [like to be more involved in difficult conversations], however, it's difficult because you can go to the meeting and be hugely supportive in the meeting, the doctors leave and you can stay, maybe give them a cup of tea and chat over some things, but then at the back of your mind you are still thinking, "I've got five other patients to look after," and you come out and the relatives go back to the patient and they might still want the support ongoing, but you still have other people to look after.

(Staff Nurse)

In terms of training it would help [to be present for difficult conversations] for when I have to start having those conversations with patients, but then I understand that it's better if it's a more intimate group of people.

(Acute Medicine Foundation Year 1 Doctor)

4. The role of nursing and auxiliary staff in SDM through their formal and informal contact with patients and families is largely overlooked.

We often have casual conversations with patients while washing them, like you ask them about their past. They will then often say that they don't think they have long to go, or what they have or haven't told the family.

(Healthcare Assistant)

5. Poor patient awareness and readiness to discuss their future treatment and care is a key barrier to effective SDM.

The actual end-of-life discussions are often much more straightforward, because you can see the patient is dying and the family can very clearly see that the patient is dying, and if they have a cancer diagnosis then everybody feels comfortable that that is something that inevitably leads to death.(...) With chronic disease, patients often bounce in and out of hospital multiple times before reaching their terminal illness and often relatives see them going from looking unwell to well again to unwell to well again (...), so therefore to use this opportunity to say, "We're worried they're in this revolving door situation," is often met with a degree of disbelief.

(Consultant)

It's often the surprising ones that have been in and out or are really frail or in a wheelchair and the family aren't realistic at all.

(Acute Medicine Specialty Trainee)

6. **As a result of system pressures nurses are rarely able to join medical ward rounds, thus limiting their critical contribution to SDM processes.**

*We don't really get the opportunity to go on ward rounds,
because we're too busy doing IVs or medications.
(Staff Nurse)*

*Most ward rounds we don't have a nurse with us. I think that would be very, very helpful, because (...) the nurse definitely knows the patient better than the doctors [do].
If we had a nurse with us that would be great for everyone, most importantly the patient.
(Foundation Year 1 Doctor)*

7. **Conversations and their outcomes are often poorly documented in patients' medical notes.**

*I think where there are major decisions made about 'ceiling of care' or DNACPR decisions, I think those are quite well documented. The more preliminary discussions and updates on condition and raising concerns that maybe they're worse now than they were 3 months ago,
I don't think these are routinely documented well.
(Consultant)*

*Conversations on the whole are not well documented. (...) I don't think we're very good at it unless you're in defensive mode and think you might get a complaint.
(Specialty Trainee)*

8. **Currently, discharge letter templates do not encourage inclusion of anticipatory care planning (ACP)-related information or prompts for community-based care professionals, leading to such information being omitted.**
9. **Staff currently do not make good use of existing information resources, e.g. the Scottish national DNACPR leaflet.**

3.2.2 Learning from the testing of draft resources and other improvement activities

All three sites tested a set of the draft RED-MAP resources aimed at staff and patients/caregivers to support shared decision-making. The development process of the first test versions of these resources was described in section 2.1.

Prompt cards for ward staff

The Project Manager briefed participating ward staff about the aims and use of the cards during routine staff meetings. Both nursing and medical staff of all grades were given copies of the cards and it was left to the individual teams to identify the most manageable approach for them

regarding testing and providing feedback. Some teams focused their initial rounds of testing on their senior medical staff with existing expertise in conducting difficult conversations. Others incorporated the cards into communication role play exercises with their junior staff.

Qualitative feedback on the RED-MAP resources

In the evaluation, interviewees were very positive about these resources, although the scale of use was small and varied.

“I know that the RED-MAP conversation prompts are now being used with trainees.”

“I’ve seen the conversation prompts for staff – the junior doctors have them in their rooms. One of them was looking at one yesterday before they went to talk with a patient about something. I think these cards could have a really positive impact on patients and families. I mean, any activity like that, getting people to communicate better, with help, is important.”

(Consultant)

“Our Building on the Best work has now been expanded and embedded into the whole quality improvement process across the acute hospitals. We’re now fully linked into the Health Board’s Deteriorating Patient programme, which has two arms – the escalation arm, and the care approach for people whose health is deteriorating with limited reversibility. This latter arm is an area which is key for us. You have to recognise that resuscitation/sending people to intensive care isn’t going to work for some patients. They are the most challenging scenarios, and the focus of this project. So the quality improvement programme for the whole of the hospital is keen to build on this project. We have three QI advisers who are now going to help us roll out the intervention, which is just about to start. Effectively, we’ve mainstreamed it, which is really exciting.”

(Site Lead, Consultant)

In other cases, there was enthusiasm for the resources although they weren’t being used at the time of the interviews:

“We are very enthusiastic about using the cards, information and posters, but it’s just overcoming challenges that have come up for us. We are trying to embed things here without any additional resource. These are things that need to be done in our own time.”

(Site Lead, Consultant)

“I think even just reading through the resources has helped me with how I speak with patients. I’m using some of the conversation prompts already, even though we’ve not implemented them across the ward. There is definitely a gap for using the RED-MAP cards...these resources give control back to the patients, which is really important.”

(Consultant)

In relation to the cards specifically, interviewees noted that changing practice regarding communication style can be more challenging with senior staff members:

“It can be hard to change their habits/communication style as they’ve been doing it for a long time, and they have their own style.”
(Consultant)

“I think something like this needs to be introduced earlier, at medical school in training. For doctors who have already trained, it can be harder to be suddenly communicating in a different style, person-centred. You have to try and adapt your style, and that’s hard.”
(Consultant)

All sites were issued with a small number of posters and leaflets, targeted at patients and families, for testing. Again, it was left to the individual ward teams to organise the testing and evaluation processes in a way that was appropriate and manageable locally.

As at September 2018 no feedback had been secured on the leaflet and poster.

Other improvement activities

Alongside resource testing, some staff teams undertook improvement activities that were prompted by findings from the scoping of current practice in their wards. As such, these activities were specific to their individual needs and priorities.

Summary of site -specific improvement activity	Status	Next steps (where applicable)
Change current mid-day board round from consultant handover only to also involve the junior doctor and nurse responsible for each patient	Embedded	Refine information discussed to explicitly talk about treatment goals for every patient
Introduce an additional multi-disciplinary board round to enhance team decision-making and information transfer	<i>Under development</i>	
Enhance the knowledge and experience gap for junior doctors regarding conducting difficult conversations by developing more structured methods of training, e.g. simulation and role play	<i>Piloted</i>	Plan to repeat
Support patient liaison/advocacy role played by healthcare assistants by providing enhanced communication training	<i>Not yet possible due to manpower reduction</i>	
Update ward information leaflets to include end-of-life care	<i>Design students involved</i>	Further iterations
Introduce a process to record details of ward-based care	<i>Identified as needing action but no progress yet</i>	
Trial bespoke lunchtime training sessions with the local Palliative Care team for all ward staff	<i>Piloted</i>	Plan to repeat
Create a patient-held care update sheet informed by ward round and MDT discussions	<i>Identified as needing action but no progress yet</i>	

Qualitative feedback on these site-specific improvement activities

Site A had changed their current mid-day board round from consultant handover only to also involve the junior doctor and nurse responsible for each patient. Interviewees described this activity as “fully embedded” and spoke of perceived improvements in practice as a result:

“The freedom of communication is so much better between staff now...This has been a great way of enriching what we do here...It feels like it works. We’re now asking staff what initial plans were overnight, and we’re getting information fed back to families and helping to make changes for people. These changes...have been so clearly beneficial. We are using this approach moving forward now, it’s as simple as that.”

(Consultant)

“From my perspective, it provides a better opportunity for all staff who know the patients to catch up with others during the middle of the day. The nurses didn’t used to be involved in this, and as a result some information would be missed, or picked up wrongly by other members of the team. Now everyone is involved in the conversations, so everyone is working from the same page. It gives staff a much clearer indication of what will happen with each patient over the next few hours, which is a really good thing.

That’s got to be good for patients and families too.”

(Nurse)

This change was also viewed as sustainable in the short to medium term:

“This has been really easy to implement...we didn’t need to make any adjustments to it, and yes, I’m confident that in six months’ time this will still be running.”

(Nurse)

Site A was also in the process of a) introducing an additional multi-disciplinary board round to enhance team decision-making; and b) developing more structured methods of training for junior doctors regarding conducting difficult conversations. It was too early to be able to comment on the differences that these activities had made.

3.2.3 Learning about the effectiveness of the programme, and about the strengths and weaknesses of the approach

Qualitative Feedback on the Programme

Strengths of the BotB programme

1 Fit with existing initiatives

Several interviewees noted that the BotB programme was timely, in particular because of wider policy and practice initiatives operating at local and national level:

“It fits nicely with involving patients in decision making, and realistic medicine. That could be highlighted a little more moving forward, linking the programme into its wider context so staff can see how it fits in straightaway.”

(Consultant)

“There is a cultural shift happening here, and BotB aligns well with the direction of travel of these policy and healthcare changes...We have a great platform for moving forward and we are poised to move forward. It may take a few years to do that though.”

(Site Lead Consultant)

2 Objectivity

Interviewees welcomed the scoping phase of the programme, which was undertaken to establish a baseline understanding of current challenges and opportunities for improvement. The objectivity with which this exercise was conducted was appreciated by staff:

“BotB provided us with the capacity for an objective overview of what we’re doing, which has been really useful, especially given how busy this environment is.”
(Site Lead, Consultant)

“The work that the Project Manager did was enlightening. It was good to have someone come in from the outside, with no clinical background, and do the work that she has.”
(Nurse)

“The initial scoping exercise was really helpful for us to reflect on what we’re doing. It wouldn’t have been possible otherwise to do this. Having an independent, objective view was so helpful.”
(Consultant)

3 Site-specific approaches

Interviewees also noted the flexibility of approach to BotB, and the importance of being able to tailor improvement activities by site:

“The changes that we’ve made are sustainable, and I think the reason for that is because we’ve been able to take part in BotB and address issues that are meaningful to us here, so we’ve been able to focus on improvements using our own agenda. BotB has really encouraged us to make our own changes.”

“Each hospital has come up with a different approach to improvement, and for us here that has fostered a sense of ownership related to the changes we’re making. That’s a really important approach to take.”
(Site Lead, Consultant)

“Being allowed to do things the way we have wanted to in Scotland has been really important.”
(Site Lead, Consultant)

Barriers to implementing activities

1 Resources

The biggest barrier to implementing learning activities was that of limited resources, specifically related to staff shortages, and staff turnover:

“We’re working at over 100% capacity just now, our winter beds crisis is still impacting on us. So in terms of getting other things done, without additional resources it’s really difficult. We’ve had staff resignations, sickness absence and early retirement of staff. All of these things make trying to do meaningful research more difficult...we’re firefighting at the moment.”

(Site Lead, Consultant)

“The barriers in running and developing the project have mainly come from staff turnover. The junior doctors are typically only here for 4 months before they rotate to another speciality. Some staff are only here with us for 4 weeks. These rapid changes make it very challenging to bring people along with us.”
“We had some challenges along the way before one key staff member left and another retired, so we lost key advocates who would have helped drive forward change and we didn’t progress with that team...If we don’t have a champion on the ward to help them that makes it harder to achieve change.”

(Site Lead, Consultant)

Competing workload priorities also presented challenges for implementation:

“It’s all about priorities really. There are some things that we have to deliver on – things for the Scottish Government or at Board level – so some work like this doesn’t get done, which is a shame as it’s clearly very relevant to us and a good fit for us.”

(Consultant)

2 Communications

Some interviewees found it challenging to communicate effectively with other staff about improvement activities, because of capacity issues and reduced opportunities for face-to-face contact:

“If I want to speak with a junior doctor and a nurse about this, you can set up times for people to come along to hear what you have to say, but people don’t have the capacity to be released from the ward.”

(Site Lead, Consultant)

“It can be hard to get people along to meetings and so we tend to share things by email, which isn’t ideal as it makes engagement quite hard...People don’t always have time to read emails either, and there are lots of initiatives going on at any one time, so there is a risk that people could see this as ‘just another thing.’

(Consultant)

General Views on the programme

Interviewees across all sites praised the BotB concept and the execution of its delivery:

“I wouldn’t change anything about the BotB process. It’s been really useful...The ability to have a Project Manager doing the work she has done in bringing people together to discuss issues has been invaluable.”
(Site Lead, Consultant)

“BotB has been a great idea – for us it’s just about how we do it in practice.”
(Consultant)

“It’s been enormously helpful to have the leadership of the Scottish Partnership for Palliative Care. They are respected by Government, by professionals, the public and the media, and by other organisations up here, and they are critical to making Scottish palliative care cohesive. They have led BotB really well.”
(Site Lead, Consultant)

“BotB has impacted on us as staff, because we talk about the concept of optimal care now, and we didn’t before.”
(Consultant)

There were no barriers identified to getting involved in the programme itself.

Views on developing future work

Interviewees were asked how future work to improve the experience and outcomes of patients and families approaching the end of life could best be supported at ward level. Staff had several suggestions, including:

1 **Obtaining additional dedicated external support**

It was suggested that additional external support would be beneficial in order to implement activities at a faster rate, as this would help to mitigate some of the challenges associated with limited capacity:

“I think in future it might be preferable to have someone external come in and speak with people on the ward about a programme like this, and perhaps have someone external come in and do the training side of things. That would be more logical to me given the time constraints here.”
(Consultant)

“This has been a valuable study, but it needs dedicated input from someone who can provide us with support for improving things. We’re missing the structure, the support and the ownership – it gets lost as there is so much else going on. So I think for the future, as part of this work, we need a support plan.”
(Nurse)

“Maybe it would be possible to adopt shared funding approaches to support someone to be here part time in a champion role, maybe across different sites?”
(Site Lead, Consultant)

2 Pre-and post-implementation data gathering

Where improvement activities had been implemented, there hadn't been the opportunity to objectively measure impacts, but interviewees were keen to do so in future. Several suggestions were made regarding future evaluation activities:

"We don't have the time to gather objective evidence pre-and post implementation. This would be really hard for us to do with current capacity levels. So I think having some external support for this within the BotB programme would have been helpful."
(Consultant)

"In future for a project like this we should think about gathering baseline data on culture, for example, so that we can evidence shifts that take place over time...Perhaps that was a missed opportunity. Having the capacity to evaluate would need to be looked at too." "The duration of projects may be worth thinking about in the future, especially in relation to measuring outcomes such as cultural change, as 2 years isn't a very long time for changes like that to occur and be apparent. So in the future it may be worth thinking about the scope for embedding extra capacity, so that higher level outcomes can be mapped effectively over a longer duration."
(Site Lead, Consultant)

3 Patient feedback

Similarly, there hadn't been an opportunity to gather patient feedback on implementation activities at the time of the interviews, and staff were unsure how they would go about this. However, they recognised the importance of gaining patient views on impact in the future:

"It would be good to collect some patient stories around impact – situations where resources have been used and they've helped. With potentially difficult conversations, you can't ask a patient how that went as it doesn't feel appropriate to. I wish there was a way to measure this though."
(Consultant)

"We haven't been able to get any patient feedback on things. We can see the impact of changes we have made/are making...but we would be really keen on patient/family involvement in evaluating the impacts of changes next time."
(Consultant)

3.2.4 Learning from patient and public involvement

Focus groups were arranged using a piggy-back approach, i.e. by approaching existing interest groups whose membership reflected the 'target population' of this project. We conducted six focus groups with a total of 54 respondents in locations across Scotland. This included: one established PPI group located in one of the three participating NHS health board areas, three older people's advocacy groups and two groups with residents attending a respite centre for people with long-term conditions. A question guide was used to give structure to these discussions. We also sought feedback from a virtual PPI network operating

in another of the three participating health boards, which generated insight from a further eight respondents. This PPI feedback informed some of the revisions of our draft support resources for subsequent testing in the participating wards.

In general, respondents welcomed the project, but questioned its ability to deliver meaningful change. They shared stories of both positive and negative experiences related to patient-carer-professional conversations in the hospital setting. Across all groups, participants reflected on the need for better and more consistent information and agreed that healthcare professionals' communication skills needed improving; this related to the use of more accessible language, compassion and respect. Furthermore, having a single named contact who is able to advise and signpost in relation to a person's care in hospital and afterwards was considered key to achieving effective communication and SDM.

Key learning points

- Piggy-backing onto existing groups is challenging as they have their own agendas, and adequately briefing groups on the background and aims of the project took a significant percentage of the time allocated.
- One-off discussions are poorly suited to this complex and emotive topic. It proved difficult to convey the subject matter clearly and sensitively and to move beyond respondents' personal stories, which limited engagement on detail in the time available.
- A dedicated user group with perhaps bi-monthly meetings may be more appropriate in order to build relationships, understanding of the project and allowed for more in-depth engagement and learning.
- A dedicated engagement budget, which is appropriate and aligned to an engagement plan and process, should be provided.

SECTION 4: REFLECTIONS AND CONCLUSIONS

After 2 years of the project there are positives and negatives to reflect upon.

Evidencing Activity and Impact

Perhaps the biggest negative relates to the difficulties experienced relating to measurement. This has affected the project's ability to describe the level of activity and the impact of the work. There seem to be several reasons for the difficulty. Perhaps the most important reason has been the failure to develop clear plans of activity at ward level (including approaches to evidencing activity and impact). This is probably a product of:

- The project approach:- participation was deliberately informally structured so as to reduce "barriers to entry" created by paperwork. The project provided no funding (and little resource beyond the scoping) and so had little leverage to insist on plans and reporting.
- Time pressure on ward staff who, having found limited time to participate, understandably prioritised *doing over data gathering*.
- Methodological difficulties of gathering patient and family feedback in sensitive circumstances.

Long Timescales

A related difficulty has been the lengthy timescales involved in getting things done. This was a theme throughout the project from gaining regulatory approvals to scheduling evaluation interviews at the end of the project. A consequence has been that many of the activities were either at an early stage of implementation or had not started at the point at which the evaluation was conducted.

Strong Engagement by many Ward Staff

Despite these challenges created by a very busy environment, short staffing and winter bed crisis the achievements of the project were made possible by the commitment of many ward staff who perceive this as an important area of their work and capable of improvement. The palliative medicine leads in each of the sites have been vital in opening doors, and in promoting and supporting ward activity. They have also been central in shaping and steering the project.

A Catalyst for Change

There is clear evidence that the project has acted as a catalyst for reflection and change. The scoping proved important in helping wards to reflect and discuss action.

Some Evidence of Positive Impact for Patients and Families

Some of the qualitative feedback suggests that the project will have had a positive impact on the experiences of patients and families. This is true of the perceived impact of the conversation prompts and also of the board round re-design.


Some Key Lessons for a Next Phase

This report captures a lot of learning which informs the future. In terms of project approach, some key lessons to take forward into a next phase of the project would be:-

- Find a way to channel more resources to ward level, whilst still ensuring local ownership and leadership of activity.
- Extra resources are particularly valuable in measuring change and evidencing impact.
- Value and measure cultural change as well as process and activity change.
- Make the availability of local resources conditional on clearly identified local leadership and the development of a reasonably robust improvement plan, including evidencing activity and impact (so far as possible).
- Find approaches to increasing input and feedback from the public, patients and families.
- Sustain activity for a longer period in order to increase (and be able to evidence) impact.

APPENDIX 1 - RESOURCES AIMED AT STAFF AND PATIENTS/CAREGIVERS TO SUPPORT SHARED DECISION-MAKING (as at December 2018 – development is ongoing)

A video to support the use of these resources by staff can be found [here](https://vimeo.com/306411058/Obd1a825f2).
<https://vimeo.com/306411058/Obd1a825f2>

Do say... Let's think ahead → 


When would be a good time to talk? Who should join us?
 Can we talk about how you are doing.../ what has changed?
 Have you thought about making plans for the future?
 How do you see things going in the next months/ years...?
 What do you like doing/ would you like to go on doing?
 Do you have questions or worries you'd like to talk about?
 It's good that you are well just now, but can we talk about what might happen when/ if...?
 If you got less well/ seriously ill, what would be important?
 Are there any things you'd like or wouldn't want for you?

Clear language Short sentences Pauses

 Let's think ahead → 



ACP-Talk 1-Starting Anticipatory Care Planning

Ready Can we talk about your health and care?
Expect What do you know/ want to ask/ expect?
Diagnosis We know.../ we don't know...Your questions?
Matters What matters to you now and in future?
Actions What can help.../ pros and cons of options...
 This treatment may not work/help because...
Plan Let's plan ahead for when/ if...

Do say... Let's think ahead → 


How have you been doing recently? What has changed?
 I wish we could..., but we don't know if...
 We hope..., but we are worried that/about...
 It's possible you might not get better because...
 Do you have questions or worries you'd like to talk about?
 Are there things you'd like or wouldn't want for you?
 This can help.../This does not work well for people with...
Clear language Short sentences Pauses

Don't talk about...
 Treatment limits/ceiling, withdrawal, futile; distressing; chance of, try...

 Let's think ahead → 



ACP-Talk 2 (Getting less well)

Ready Can we talk about your health and care?
Expect What do you know/ want to ask/ expect?
Diagnosis We know.../ we don't know... Your questions?
Matters What matters to you now?
Actions What can help... Pros and cons of options...
 This treatment does not work well/ help when...
Plan Let's plan for when/ if...

Do say... 



We hope..., but we are worried that/about...
 It is possible you will not get better this time...
 Can we talk about what might happen if you get more ill?
 Do you have questions or worries you like to talk about?
 Are there things you'd like or wouldn't want for you?
 This can help by.../This does not work when...(e.g. CPR)
 We don't know exactly what will happen or when...
Clear language Short sentences Pauses

Don't talk about...
 Treatment limits/ceiling, withdrawal, futile; nothing more we can do...

 Let's think ahead → 

ACP-Talk 3 (Talking about dying)



Ready Can we talk about your care?
Expect What do you know.../ want to ask/ expect?
Diagnosis We know.../ we don't know...Your questions?
Matters What matters to you now?
Actions What can help.../ This does not work/ help because...
Plan Let's plan good care for you and your family...

 **SPiCT™** 

Identify: people at risk of deteriorating health and dying

Unplanned hospital admissions
 Performance status is poor or deteriorating: needs personal care/care package at home.
 Depends on others for most care needs due to physical and/or mental health problems.
 Progressive weight loss and/or a low BMI; loss of muscle mass
 Symptoms: persist despite best available treatment of underlying conditions
 Person/ family focusing on quality of life, less treatment, best supportive care/palliative care

12/1/18

 **SPiCT™** 

Identify - Assess - Talk - Plan - Record - Share
 Ask 'what matters' and what can help? Make a plan

Review benefits and harms of tests, treatments and medications. Stop treatments and medicines not of benefit; avoid polypharmacy; consider anticipatory prescribing.


Refer to the specialist/ service most able to help if symptoms, holistic needs or care planning discussions are complex and challenging.

Agree current and future care plan (including an emergency/ urgent care plan) is the current anticipatory care plan/ KIS up-to-date?

Plan ahead if risk of loss of decision-making capacity (Ask about POA).

Record, communicate and coordinate care plan.

Holistic Care: physical, emotional, psychological, family, social, spiritual, cultural care.



The team looking after you might ask:

*Who are the people who help and support you?
Can we talk with them too?*

Are there other things that we could do to help you?

What do we need to know about you to look after you well?


This leaflet is new and we want to know if it is helpful and how we can improve it.

Please tell us what you think.

What matters to you?

Talking about treatment and care when people are ill in hospital

Information for patients about care planning



Building on the best

Version 10 – 24/8/18

Introduction

When someone is ill in hospital, it is important for us to talk about what is happening and what might happen if their condition changes.

The team looking after you want to find out **what matters to you**, and involve you in planning your treatment and care.

If you agree, we will talk with the people close to you to get their thoughts too.

‘Anticipatory care planning’ means thinking and planning ahead and understanding what is happening with your health and care.

Some people have a *Scottish Anticipatory Care Plan* (<http://ihub.scot/anticipatory-care-planning-toolkit/>) or another plan they have made about treatment and care.

Please tell us if you have chosen someone to have a *Power of Attorney* for you.

Here are some things you might want to ask us:

This is what I know already...
Can you tell me what has changed?

Can we talk about what’s going to happen now?

Can we talk about what is important to me and the people who are close to me?

Can we talk about the things I would like and the things I don’t want?

Can we talk about choices I have and any decisions I need to make with you?

Version 10 – 24/8/18

APPENDIX 2 – QUALITATIVE INTERVIEW METHODOLOGY

Fourteen staff members from the three participating sites were invited to take part in a telephone interview, between August and September 2018. Eight did so, including the three site leads. The interview topic guide is shown below. The telephone interviews were approximately 30 minutes long. They all took place at a time and date to suit each participant, and each participant gave verbal consent at the time of interview.

All participants had the opportunity to amend/add to their summary interview transcript before it was finalised.

Table 1: Number of interviews conducted by site

Site A	Site B	Site C
N=3	N=3	N=2

Interview questions for ward staff

1. What improvement activities (if any) did you try out as a result of the BotB programme?
2. What was the aim of these activities?
3. What difference did these activities make? Were you able to gather evidence to support this conclusion?
 - Improvements for staff?
 - Improvements for patients and/or families?
4. Did you need to make any adjustments to the activities you tried out? If so, what changes did you make?
5. Do you think you'll still be doing these activities in 6 months' time? Why?
6. *If you did not carry out any improvement activities* what were the barriers?
 - Barriers to getting involved in the project?
 - Barriers to implementing activities?
7. Any other views/comments on BotB?
8. How could future work to improve the experiences and outcomes of patients approaching the end of life, and their families, best be supported at ward level?

Interview questions for the site leads

1. What impact, if any, do you believe that the BotB programme has had at your hospital?

What evidence supports your conclusion?

- Changes in terms of relationships?
 - Changes in terms of culture?
 - Changes in terms of experience/outcomes of patients and families?
2. What have been the strengths of the programme (prompts – structure, approach, supporting local ownership, staff, organisation/management, clinical commitment)?
 3. With the benefit of hindsight what would you change about the programme?
 4. How could future work to improve the experiences and outcomes of patients approaching the end of life, and their families, best be supported,
 - at ward level?
 - in terms of programme structure/organisation?