



Shared decision making: the importance of writing clinical letters directly to the patient

Case studies

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Contents

Overview	3
Implementation	4
Recommendation 1.2.20	5
Patient interviews.....	5
Analysis of feedback.....	6
Sharing the findings.....	6
Outcomes and learning	8
Outcomes.....	8
Learning	10
Supporting information	12
Quotes	12
Contact details	12

Overview

Organisation: Southern Health and Social Care Trust (SHSCT)

Organisation type: HSC Trust

In Northern Ireland, the Department of Health formally endorsed NICE's guideline on shared decision making on 23 May 2022. In adherence to the regional chief medical officer directive (reference HSC [SQSD] 13/22), the Southern Health and Social Care Trust (SHSCT) was required to agree a clinical management lead to coordinate implementation and consider what must be done to achieve this within 12 months of regional endorsement.

Following the presentation of a project proposal paper in February 2023, the trust's senior leadership team agreed that this work was to be recognised as a corporate priority workstream for 2024/25. In June 2023, an SHSCT shared decision making (SDM) steering group was established, with senior leaders across the health and care professions appointed as co-chairpersons. Suitable governance and reporting arrangements were put in place alongside a comprehensive project work plan. Together, these mechanisms have strengthened the positive culture of SDM within the organisation, thereby ensuring people are adequately supported to make informed decisions about their treatment and care.

Implementation

As part of the initial implementation of this guidance, baseline assessment tools were completed by 6 key directorate services, which were nominated by their respective director for involvement. Following completion of the service-level baseline assessment tools, areas of non-conformity could be identified and common themes relating to why the guidance was not being met, escalated for discussion within the SHSCT SDM steering group.

Regionally, an external stakeholder meeting was also established in 2023, co-chaired by the Public Health Agency (PHA) and Strategic Performance and Planning Group (SPPG). The membership on the group includes representatives from all the HSC trusts in Northern Ireland (senior clinical leaders and personal and public involvement teams), PHA, the Regional and Quality Improvement Authority, the NICE implementation consultant for Northern Ireland, primary care representatives, and service users.

This group has been valuable for shared learning and agreeing actions that are required to collectively ensure all the guideline recommendations are met, particularly when there were recognised barriers that needed a regional approach to remedy.

Three regional task and finish workstreams, chaired by the SPPG and PHA, have a primary focus on the following:

- Development of regional guidance relating to patient letters (recommendation 1.2.20) and based on the principles outlined in the [Academy of Medical Royal Colleges' guidance on writing outpatient clinic letters to patients \(PDF\)](#).
- Development of a suitable regional multidisciplinary team (MDT) training programme and regional patient decision aid repository.
- Promotion of a regional public awareness raising campaign.

SHSCT representatives were appointed to all 3 regional task and finish groups and report back to the local trust SDM steering group to progress key actions and ensure the local and regional work plans are consistent and joined up.

Recommendation 1.2.20

Across the 6 directorate pilot areas, there was limited assurance to confirm that recommendation 1.2.20 was being fully met. While several areas were writing to the referrer and copying the person into the correspondence, this practice was not fully meeting the requirements of recommendation 1.2.20, which states that "when writing clinical letters after a discussion, write them to the patient rather than to their healthcare professional, in line with Academy of Medical Royal Colleges' guidance on writing outpatient clinic letters to patients. Send a copy of the letter to the patient (unless they say they do not want a copy) and to the relevant healthcare professional".

The trust's urology service, which formed part of the pilot work, agreed to look at this recommendation more closely, with an initial focus on those who are currently being cared for within a urology cancer pathway.

Patient interviews

Following an initial MDT meeting in February 2024, a series of meetings took place initially between Macmillan engagement staff and members of the SHSCT SDM project team that was primarily composed of urology and cancer MDT members. These meetings determined the purpose and focus of the project, agreement on a suitable project methodology, as well as what would be achievable within capacity and the key areas where learning and improvement was required.

To provide a safe and empathic space, the project team agreed that patient interviews with Macmillan peer facilitators would likely optimise engagement and sharing of information. A total of 30 patients who were on the SHSCT urology cancer pathway were randomly selected from patient lists, with 15 people subsequently consenting to take part. A total of 7 Macmillan peer facilitators carried out the interviews on a one-to-one basis, via telephone or online, depending on the person's preference.

People were asked before the interview to think about or identify a specific letter they had received, either from a nurse specialist or medical professional, which would be used to base the conversation on.

The Macmillan peer facilitators carried out each interview, as directed by an agreed 'conversation guide'. This guide was co-produced by the Macmillan peer facilitators and was designed to support the interviews based on the key areas within the NICE guideline.

This guide ensured consistency and comparability across all interviews. After each interview, peer facilitators completed a feedback report and submitted it to the Macmillan engagement team.

Before the interviews took place, the Macmillan peer facilitators took part in a briefing meeting with key members of the SHSCT SDM project team, to ensure they had clarity of purpose and intent and to be able to respond to any queries from facilitators about the process.

Analysis of feedback

The Macmillan engagement team used Braun and Clarke's 6-step thematic analysis method to evaluate the peer facilitators' feedback:

- phase 1: data familiarisation
- phase 2: systemic data coding
- phase 3: generating initial themes
- phase 4: developing and reviewing themes
- phase 5: refining and naming themes
- phase 6: writing the report.

Peer facilitators reviewed the final report to ensure accuracy and authenticity.

Sharing the findings

Following completion of the report and approval by the project team, the report was shared with the co-chairs of the SHSCT SDM steering group and the Executive Director of Nursing and Midwifery, who was the appointed director lead for this work. Upon their agreement, the following actions were taken:

- A finalised report was presented to the SHSCT safety and quality steering group on 29 January 2025. This was in keeping with the terms of reference and agreed governance arrangements for the SDM steering group.
- The report was presented to the SHSCT urology MDT on 6 February 2025, to provide

feedback and learning from the clinical teams directly involved in the project. Approval was given from the senior leadership team to finalise and submit this work to NICE for publication as a case study.

- The report was shared with the SHSCT SDM steering group.
- The report was shared with the chairperson of the regional task and finish group relating to clinical letters, to support the development of regional guidance for healthcare professionals.
- As part of the SDM steering group communications plan, a short PR video is now being planned to showcase the role of the Macmillan peer facilitators in this project and the key outcomes that have been identified. It is hoped that this will be completed by September 2025.

Outcomes and learning

Outcomes

Timing and impact

It was evident from feedback that many experienced significant shock or trauma on receiving a cancer diagnosis. In fact, one cannot underestimate the challenges some people reported in coming to terms with a diagnosis. A significant number of people reported the relief experienced by receiving the letter as it helped consolidate the information they had been given at diagnosis, helping them process their diagnosis and understand their results and how decisions had been made about their future care and treatment.

For those awaiting results (typically scan results), the timing of the letter was of utmost importance. People spoke of the relief they felt if their letter was received in a reasonable timeframe, saying that it brought a deep sense of reassurance. One person said they had to be proactive in seeking out results if the letter did not arrive in time and another described how receiving their letter was particularly welcome due to issues contacting their GP.

Language and accessibility

In most cases, feedback confirmed that the letter was clear, concise and easy to understand, and was a support to people in talking to loved ones about their condition and treatment plan. One person highlighted the need for accuracy, especially in terms of projected timescales for when they would be scheduled for their next scan or diagnostic procedure. With current service pressures, this can be difficult to achieve but the need to set more likely and achievable timescales was important.

Almost all people observed that the language in letters, if directed to them, tended to be very clear. However, those who received a copy of a letter that was directed to another medical professional (for example, GP) did report greater concerns about the language and, in most cases, it was referred to as being 'jargonistic', making it more challenging to understand. However, some people noted that any of the information that was difficult to

understand, or required further explanation, they were generally able to get during face-to-face appointments.

Decision making

There was a range of responses to this question, indicating a mixed level of involvement in decision making. Some indicated they just placed their faith in the expertise of those treating them. One person described the letter as a confirmation of decisions they had already made, but that the letter helped them feel involved in their care plan and this was important to them. Some letters however raised concerns about the wording ("letter said my operation was classed as 'major' and I was imagining a really long and complicated procedure"), but a follow-up conversation with the clinical team provided reassurance. One person did report having no involvement in decision making, saying, "The letter did not help in this regard. All decisions about my care were made without my input".

Support

Overwhelmingly, people noted the immense support that was provided by the clinical nurse specialist (CNS) to resolve any issues or concerns. Prompt reaction to queries and requests meant that people felt less anxious, and it emerged that the CNS was clearly the go-to person for concerns or complaints. Often this point of contact was critical due to the current difficulties in accessing GP services coupled with "issues of privacy when speaking to the receptionist and also difficulties getting appointments".

Further feedback

At the end of each interview, an opportunity was given to people to talk about anything else they felt was relevant to the conversation, that they may have missed in previous sections. It was one way of eliciting any suggestions they may have for improvements to any aspect of the letter writing process.

- **Positive overall experience** – a significant number of the people interviewed said that they were satisfied not only with the letters, but with their overall treatment.
- **Lack of opportunities to meet with the consultant** – while one person was very happy with their letters, they were disappointed in not being able to see their consultant occasionally as this would have greatly helped with their psychological recovery from their condition.

- **Time between letters** – one person mentioned their concerns around gaps between letters, which they found "long and difficult". This added to their fear they could get "lost in the system".
- **Lack of consistency with consultants** – one person was very complimentary about their treatment at the hospital, especially regarding the nurse, but felt that the process was made more challenging through a lack of consistency with consultants.

Learning

The project outcomes clearly illustrate the extent to which rich and meaningful insights were captured through the engagement process of peer facilitators with a cohort of people on the urology pathway.

Shared understanding and authentic engagement have underpinned all conversations, and people shared their experiences openly and honestly with the hope that their contributions will make a meaningful difference to people in the future.

The key learning points are:

- People can often feel a sense of shock and trauma on receiving a cancer diagnosis, and a letter received post-diagnosis can play a significant role in helping them better understand their condition as well as process all the information they have been given.
- It is important that letters are sent to people as soon as possible after appointments as this greatly reduces anxiety as they wait for information. It is acknowledged that there are overall delays in the health system, which can have a follow-on impact on the timing of treatment, and letters where possible should contain accurate information about this.
- Letters play a significant role in helping people understand their condition as well as their care and treatment plans. They are also a useful tool to help them share relevant details with loved ones.
- Letters written directly to people were mostly clearly communicated and easily accessible. However, letters where the person received a copy of correspondence 'about them' to another medical professional tended to have significantly higher levels of jargon, and as a result were less accessible.

- Involvement in decision making is variable, with many placing their faith in the expertise of their medical team. In some cases, letters represent confirmation of decisions already taken in relation to their care, and in a small number of cases, people reported no involvement whatsoever in decisions about their care.
- The CNS plays a highly significant role in supporting people with concerns and is clearly the go-to person for problem solving.
- Overall, people expressed gratitude and praise for their medical teams, and the positive impact of the letters is apparent. However, there remains multiple suggestions for improvement, which are highlighted in this report.

Supporting information

Quotes

During the interviews, some people stated that the letter supported them when talking to loved ones about their condition and treatment plan:

"I live alone, but the information in the letter meant that I had the knowledge necessary to communicate my situation to my 2 sons."

"It was good to share the letters with family and to sit down and read the letters together."

"I was very happy with my letter, as it was clear and easy for me to understand – I wouldn't change anything!"

"I had already decided that I would be having treatment as advised, so the letter did not change this situation. However, I was pleased to be involved and happy to be informed in my own care."

"I'm happy that there were clear contact details on the letter and that all the information was accurate. I also welcomed the contact I had with the specialist nurse who phoned me about twice a year."

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