

SIGN 167: Care of deteriorating patients
Consultation report on: Plain language summary

The consultation

This was an usual topic and it was difficult to involve people in the clinical guideline who had ‘true’ experience of the topic, so we decided to hold a meeting with a small group of people with lived experience of various conditions and members of the public to provide feedback on the plain language summary. We wanted to make sure the plain language summary was:

- readable
- relevant
- useful, and
- sensitively worded.

We invited HIS public partners and people who had expressed an interest in joining the guideline group to participate in the consultation meeting. 7 individuals participated in a meeting on 5 July 2023 to discuss the consultation draft of the plain language summary. Feedback gathered during the discussion has been summarised. The findings were considered for incorporation into the draft before being approved for publication. All participants completed a DOI form.

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1. What is your overall impression of the plain language summary?			
	Feedback	Group Response	Editorial response
	<p>The draft was well received by most and it was found to be very readable. The group suggested that something a bit more abbreviated is useful although the guideline itself too 'medical'. It was felt that the less that's said the better and this is useful as something for people to fall back on and allows people to challenge things.</p> <p>The draft is clear, but some parts are still clinical but might need to be.</p> <p>Might not be a helpful document for some but good to give people the option.</p>	<p>Thank you. We are keen to make this available so people know what care they should expect to receive. We have shortened sentences where we can and explained some clinical terms.</p>	<p>✓</p>
	<p>The term "deteriorating patient" needs to be clearly defined, as someone with no experience won't always know what this is.</p>	<p>Added to beginning of document</p>	<p>✓</p>
	<p>Need to highlight the importance of communication between healthcare professionals and patients, carers, and families.</p>	<p>We have mentioned involvement of carers/families in decision making to reflect the guideline recommendations.</p>	<p>Strengthen by adding that ACPs should be shared rather than can. ✓</p>
	<p>Should include mention of power of attorney, how it works and where to go to set it up.</p>	<p>Outwith guideline remit but have signposted to website where people can get information on appointing a PoA.</p>	<p>✓</p>

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2. Please tell us what you think about the way the booklet is written			
Do you think that the language and tone is appropriate?			
	Feedback	Group Response	Editorial response
	The language is appropriate and tone is sensitive.	Thank you	✓
	Could change “feel free to raise concerns” as “feel free” puts the onus on the family/carer to decide if they should say or not.	Agree – changed.	✓
	Should check the wording around sepsis and bacterial vs viral to make sure it’s correct and understandable.	Checked with clinician and this is correct but have now removed first sentence as not necessary.	Add explanation of what sepsis is. ✓
	Some NHS-specific terms (structured processes, handovers, checklists) should be explained for those who haven’t heard these before.	Explained these	Explain that structured processes are written guidance for staff on what steps to take when a patient deteriorates. What they then decide to do is called a structured response. ✓
	Like how the guideline mentions that there isn’t always an answer for deterioration. This is important as sometimes deteriorating patients don’t get better. Could add this to the definition of “deteriorating patient”. Could also link this to raising concerns with staff, and ask them to explain what’s happening rather than just flagging.	Added that there is often no explanation for patients deteriorating. Added that people can raise concerns with staff if they noticed deterioration.	✓ Add that patients may get more unwell as condition progresses. Add that healthcare professionals should give you information that you can understand to help you take part in decision making. ✓

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3. Please tell us what you think of the content			
Does the content help patients and the public understand what the latest research and good practice supports around monitoring patients in hospital and caring for the if their health becomes worse?			
	Feedback	Group Response	Editorial response
	Useful to include anticipatory care plan, but need to make sure to define this. People will be able to ask for this if they know it should be happening and is best practice.	Added to this section to help explain	Add that an anticipatory care plan can be documented at any point in your care, but it might be particularly relevant if there is a chance your health may become worse suddenly. ✓ Add that during the handover the teams will discuss your health, clinical observations and appropriate care. ✓
	Slightly simpler than the guideline and clearer,	Thank you.	✓
4. Please tell us what you think of the way the booklet is presented			
Is the layout easy to read?			
	Feedback	Group Response	Editorial response
	The layout was well received. People liked the use of “what, when, and where” as these are the questions that patients and carers will ask/want to know. Using boxes rather than continuous text is best, since people are more likely to retain what’s there if things are separated out and will read on. Pages aren’t too busy.	Thank you	✓
	There are too many orgs included. People are unlikely to	To reduce size of document and to make this	✓

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	<p>contact any of these so a link to NHS inform or a library of charities is better. Break these up and have in main text rather than huge list at end. Only include SAMH for mental health organisation as this is better than others.</p> <p>This may be helpful, as deteriorating patients can be suffering from a whole host of conditions.</p>	<p>more useful we have included links to organisations in specific sections. Included link to SAMH at beginning of document beside NHS Inform so signposting come early on.</p> <p>Link to NHS inform page on different conditions</p>	
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