

This document is a translation of the original assessment in Swedish by SHK of the response to the recommendation. In case of discrepancies between this translation and the Swedish original text, the Swedish text shall prevail in the interpretation of the assessment.

Swedish Association of Local Authorities and Regions

SHK's assessment of the response to the recommendations from the Swedish Association of Local Authorities and Regions

The Swedish Accident Investigation Authority (SHK) published final report SHK 2023:02 on 20 January 2023, concerning a serious incident involving a delay in care in relation to an indeterminate abnormality of the pancreas.

The report issued a total of five safety recommendations, two of which were addressed to SKR (SHK 2023:02 R1 and R2).

The Swedish Association of Local Authorities and Regions was recommended to consider whether there is a need to clarify how standardised care pathways should be used at an early stage, for example in primary care when an indeterminate abnormality is identified as an incidental finding, and, if so, to take steps to do so. As part of such consideration, it would also be appropriate to address the ambiguities identified in this investigation in relation to the standardised care pathway for GEP-NET (R1).

On 18 April 2023, SKR submitted its response to SHK's safety recommendations. In a general comment, SKR states that the delay that occurred could also have arisen in other cases involving more than one region. SKR further notes that web-based services are already available and used regionally to share information about patients, but that uptake of these systems is low.

With regard to recommendation R1, SKR refers to the annual review of the national clinical guidelines. For example, the guideline for pancreatic cancer was reviewed in December 2022 and included, among other things, clarification of the criteria for well-founded suspicion. The clinical guideline group for GEP-NET discussed a possible revision in April 2023. It concluded that the clinical situation should determine the choice of action and that no further clarification was therefore necessary.

SHK notes that SKR does not set out in its response any consideration of the use of SVFs at an early stage, as called for by the recommendation. SKR further states that SVFs are not intended to serve as algorithmic decision-support tools for the management of indeterminate abnormalities. However, this was not what the recommendation concerned.

Incidental findings are nevertheless becoming increasingly common and are something that healthcare services need to manage. In this context, it is important to emphasise that the objective of providing good and equitable care throughout Sweden is complicated by the large number of healthcare providers and, in some cases, the use of locum doctors, which may affect continuity of care. Although responsibility ultimately rests with the responsible authorities, which are accountable for organising healthcare within each region, it may be questioned whether enough has been done to support primary care at the initial stage of a standardised care pathway.

The response indicates that the clinical guideline group for the GEP-NET standardised care pathway considered the need for clarifications, which partially addresses the recommendation. However, the group concluded that no such clarifications would be made.

Overall, SHK considers that the recommendation has not been addressed and assesses the response as unsatisfactory (**Closed – unsatisfactory response**).

SKR was also recommended to conduct a review of the standardised care pathways and the milestones selected for the waiting-time measure, with the aim of better capturing the entire diagnostic and care process. Important evaluation parameters could include, for example, whether there are differences between regions in the extent to which cancer has progressed when patients enter an SVF, as well as survival and recurrence rates. Potential displacement effects and other adverse effects of SVFs are also of interest to map and quantify. This may be carried out within existing organisational structures (R2).

In its response, SKR states that SVFs are subject to ongoing evaluation and that the treatment of patients is continuously evolving. SKR further notes that other evaluations have been carried out, including by the National Board of Health and Welfare, concerning the complexity of measuring and reporting, for example, displacement effects. SHK has also identified and described in its final report the results of evaluations previously undertaken.

In its response, SKR has merely stated what other stakeholders have done in relation to work on SVFs. The response does not indicate what measures SKR itself intends to take. The recommendation cannot therefore be considered to have been addressed, and the response is unsatisfactory (**Closed – unsatisfactory response**).

Yours sincerely,

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Chair of the Investigation