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Department for Health and Medical Services
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This document is a translation made by SHK of the original response in Swedish to the safety recommendation. In case of discrepancies between this translation and the Swedish original text, the Swedish text shall prevail in the interpretation of the response.

Statens Haverikommission

102 29 Stockholm

Consultation response – Consideration of recommendations addressed to the Swedish Association of Local Authorities and Regions (SALAR) by the Swedish Accident Investigation Authority in report SHK 2023:02

The Swedish Association of Local Authorities and Regions' views

Investigation by the Swedish Accident Investigation Authority: delay in care, SHK 2023:02

The Swedish Accident Investigation Authority (SHK) has requested that action be taken in response to the recommendations addressed to SALAR in report SHK 2023:02 concerning a serious incident involving a delay in care relating to an indeterminate change in the pancreas.

General comment

The delay in care described in SHK's report 2023:02 could have occurred in relation to most diagnoses involving care across regional boundaries. The issue lies in communication between the regions and in the fact that current IT systems are unable to transfer information in an optimal manner.

Systems have been developed to facilitate communication between healthcare providers. For example, the Regional Cancer Centre Stockholm Gotland has developed a web-based service, the Referral Portal, which supports healthcare providers by enabling rapid and secure transfer of information between services, irrespective of patient record system or regional boundaries. Unfortunately, demand for this service has been too limited.

There is a significant need for future healthcare information systems in which information can be shared across regional boundaries and between all providers within a region, regardless of whether they are privately operated or not.

Delays in the care pathway concerning suspected pancreatic cancer are particularly serious, as the time from detection to treatment is crucial to the patient's continued eligibility for treatment. Delays of this kind may result in a potentially curable disease becoming incurable.

Measures taken

SKR has been asked to provide information on the measures taken in response to the recommendations set out below:

Recommendation: 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, take steps to do so. As part of such consideration, it would also be appropriate to address the ambiguities identified in the standardised care pathway for GEP-NET in this investigation (see section 2.3.2). (SHK 2023:02 R1)

Response: Standardised care pathways (SVFs) are reviewed annually by the national clinical guideline groups. In the revised version of the SVF for pancreatic cancer, published in December 2022, the criteria for well-founded suspicion of pancreatic cancer have been clarified.

However, SVFs are not intended as algorithmic decision-support tools or process descriptions for the management of indeterminate abnormalities or incidental findings. The SVF for GEP-NET was discussed by the national clinical guideline group in April 2023 in order to determine whether a revision was required. The group agreed that the clinical situation determines the choice of diagnostic measure. It is therefore difficult to clarify the SVF description further, and the clinical guideline group considers that referring to the clinical guideline is appropriate. Consequently, the SVF for GEP-NET will not be amended during 2023.

Recommendation: 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 severity of cancer at the point 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 (see section 2.3.2). (SHK 2023:02 R2)

Response: The National Board of Health and Welfare has evaluated the SVF initiative regularly, and a new evaluation is under way in 2023.

As cancer care is continuously evolving and new treatment and diagnostic options are introduced on an ongoing basis, it is very difficult to use

recurrence or survival as evaluable variables for SVFs. In addition, the waiting times in SVFs are calculated on the basis of what constitutes value-adding time from the patient's perspective; they are not set from a survival perspective. Regional differences in the severity of a cancer diagnosis when a patient enters an SVF depend both on how well the healthcare services available to the patient are functioning and on the stage at which the individual patient seeks care.

Displacement effects are of considerable interest, but they too constitute a complex area for evaluation. The National Board of Health and Welfare has been tasked with monitoring this issue, and the regions are required, through the action plans submitted annually to the Ministry of Health and Social Affairs, to report any anticipated displacement effects.

Differences in the regions' waiting times and patients' satisfaction with SVFs, as measured through PREM surveys, are monitored and evaluated regularly on cancercentrum.se and in annual reports.

Swedish Association of Local Authorities and Regions

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