

I write in response to your letter of 24 April, asking me to comment on the 4 Terms of Reference for the Governance of Health and Social Care review and answer a further 3 questions, in my capacity as Trustee of the Antoine Trust. This is a local charity which has been supporting paediatric oncology in the Island for the last ten years by providing funds not only to families but also to HCS for children's cancer related matters.

In order to make our responses more relevant to your review, we have necessarily shared detail below which should be considered as sensitive and confidential. We have assumed that such information will be treated as such by you and whoever else is given access to this. If further specific information is required, please let me know.

Our major areas of interaction with HCS have been in:

- a) the establishment of a new staff role within HCS, being that of the Paediatric Oncology Nurse (PON), in 2012, and providing funding for that role from then until 2018, when HCS took over that funding.
- b) provision of funding for training of the PON and other staff in the area of paediatric cancer care

Since 2019, we have been in discussion with HCS in relation to the establishment of, and funding for a new role to provide assistance to, and continuity cover to the PON. Despite this being agreed in principle with management within HCS in July 2022, no material action to deliver this has occurred.

It should be noted that the creation of both the PON role, and the new assistant role have been in response to needs identified by the relevant clinical leads; our role has been to support this, and to provide funding where that has not been achievable from within HCS budgets, with the intention of providing enhanced care without marginal costs to HCS.

In the same order as your letter, our comments are as follows:

1. May we suggest that you define and have a clear description of 'governance arrangements' if you wish to obtain targeted, relevant and therefore meaningful results.
2. We welcome your focus on 'accountability, quality of service and value for money'. (see our answer to your second question below)
3. This term of reference suggests that no assessment of the adequacy of the follow up of the recommendations made by the Comptroller and Auditor General has been made over the 5 years since 2018. If this is indeed the case, I'd be surprised and disappointed.
(Even as a small charity we pride ourselves on 'following up' on matters, whatever they are as it is common sense and good standard practice in whichever industry or organisation)
4. We note the intention to examine the effectiveness of financial management within HCS. Our experience suggests deficiencies in this area as explained at '2.' below.

Before we answer your additional questions, we need to point out 2 facts:

Firstly, our interaction with Health and Community Services is in relation to our charity's activities and therefore extends to paediatric oncology and ancillary matters only. We cannot therefore comment on the wider HCS remit.

Secondly, we do not have the details of the overall current or proposed Governance arrangements within HCS, and can therefore only comment based on our interaction with relevant departments and decision makers.

Bearing in mind the above caveats, our responses are as follows:

1. Our experience of dealing with HCS over the last ten years is split, depending on the services involved.

- The medical personnel, in our opinion delivers 'Quality care'. We believe this is thanks to competent and dedicated individuals, who care for their patients, despite or regardless of 'governance arrangements'.

- The 'management' personnel, on the other hand, has been found lacking, with little apparent understanding of the notions of 'quality' or 'care'. We appreciate, and hope, this may be down to a few individuals rather than endemic.

This has been evidenced by slow and ineffective decision making in the establishment and management of the roles that we have supported. Specifically, we have experienced material delays in the decision in 2018 for HCS to assume financial responsibility for the PON role, with a final decision being made a matter of weeks before our funding commitment terminated. This necessarily created huge uncertainty for the staff member then employed as PON, who cannot have known whether their role would continue. Similarly, while we have been informed that management has approved the creation of the new PON assistant role, to be funded by our charity, no material progress has been made in contracting for that role or our support over a period of approximately 11 months.

The net result of these governance deficiencies has been a reduced quality of care, with no cost saving to HCS, as well as presumably disenchanted frontline staff.

2. Some of the challenges we have faced illustrate the points made above and relate to governance as handled by 'management and admin' personnel:

- We have experienced a basic lack of communication, with staff repeatedly failing to answer emails or telephones or follow up on previously agreed actions and deliverables. For example, a 3 months delay to respond to an email is not uncommon.

- The many layers of management have made it difficult to hold anyone accountable, or find anyone with decision making capacity. This has led to stalemate situations and has seriously hampered our charity's ability to deliver on its commitments in a timely manner.

- We have, several times, raised the issue of HCS' lack of long term plan or vision, (and therefore ancillary budgeting) with various 'managers' as it was becoming more and more difficult for us to deal their up hazard approach. No one seemed to understand the benefit of 'a plan', or if they claimed to, they were quick to blame the failure unto the demands of another committee or governing body. They also failed to appreciate the consequences of this lack of planning as it jeopardises our own plans, budgets and fundraising, which in turn will deprive HCS of the support and funding we could have otherwise provided to the service.

3. As mentioned at the beginning of our answers section, we do not have the details of the 'recent governance proposals' and cannot therefore comment on whether any lessons have been learned.

Having said that, our experience has shown no material change - and if anything a deterioration - in effective decision making and communications since our involvement began in 2012.

We would hope that lessons learned would include gripping HR and reducing quantity in favour of quality. This should help manage finances to redirect funds where they are most needed and make better use of available funds, including understanding the role of the charitable sector in this respect. Finally, grasping the fact that action, not surveys and reviews, will solve HCS' tribulations, should be the main lesson.

Should you wish to discuss any of the above points further, please do not hesitate to contact us.