

National Organ Retrieval Service (NORS) Review

ABOUT THE REVIEW

Challenge Event

London, 17 July 2014

An independently Chaired Review of the National Organ Retrieval Service (NORS) has been commissioned by NHSBT, to ensure the service has the capacity to meet the requirements of the organisations <u>Taking Organ Transplantation to 2020 Strategy</u>, allowing for the expected growth in activity, whilst also providing value for money.

Senior representatives drawn from the profession and NHS providers and commissioners have been asked to evaluate the effectiveness of the current NORS provision and make recommendations to ensure the future provision of a quality service across the UK.

NHSBT has commissioned NORS on behalf of all four UK countries since April 2010. NORS is a 24/7 organ retrieval service and is provided by seven abdominal and six cardiothoracic teams from transplanting centres across the UK.

The review will engage with a range of stakeholders and recommendations will be presented to NHSBT in 2015.

Who attended?

This event was attended by experienced clinicians, commissioners, policy makers and lay and patient representatives from across the UK.

What was the purpose of this event?

The event was designed as a challenge event (see box on page 5). It was a key opportunity for stakeholders to engage with and contribute to the work of the Review and for the team to gather vital input from across the stakeholder community.

The Review expected that this event would:

- Look at what has worked well and what could be better.
- Consider current issues and future challenges.
- Help to identify the main opportunities and priorities for improvement.
- Acknowledge the challenges facing the Review as it carries out its task.

A further event is scheduled for 16 October 2014.

How was the event run?

The event was designed to create a conversation between the Review and the stakeholder representatives who attended.

It began with a presentation from the Review Chair, Kathleen Preston, who set out the Review's context and task and outlined the principles under which the Review Team has been asked to carry out its work.

Delegates were presented with the outline plan and chosen approach. They then heard some background to the establishment of NORS and were presented with an overview of some trends in retrieval since the service was established

This was followed by an open discussion, where delegates were asked to consider the key challenges and main priorities for improvement.

In the afternoon, three of the Review's Workstreams, looking at issues around Workforce, Capacity and Commissioning (including funding), were presented and delegates were asked to provide advice and insight on:

- What the issues might be
- Where opportunities for improvement may exist
- What the challenges are
- What the potential 'fixes' might be (areas for recommendation)

The NORS Review

Background and summary

Since April 2010, NHSBT has commissioned 13 organ retrieval teams across the UK to deliver a 24/7 national organ retrieval service, in accordance with Recommendation 10 of the Organ Donation Taskforce recommendations (A UK-wide network of dedicated organ retrieval teams should be established to ensure timely, high quality organ removal from all [DBD and DCD] donors).

The system has worked well so far, contributing to achieving the 50% increase in organ retrieval against the 2008 baseline. However, in line with best practice for commissioning of services, NHSBT has agreed that a Review should be undertaken, to ensure the Service meets the requirements of the TOT 2020 Strategy.

The NORS Review is a stated aim within the strategy and will ensure that this service has appropriate flexibility to meet demand and contribute to the improvement of transplant rates: Outcome 4 of Taking Organ Transplantation to 2020 states that "Action by NHBST and Commissioners means that better support systems and processes will be in place to enable more donations and transplant operations to happen."

Aim and objectives

The aim of the Review is to benchmark current service provision, identify any gaps or shortfalls and make recommendations in line with the following principles:

- Equity and timeliness of access to a retrieval team for all potential donors whilst acknowledging geographical challenges
- Sufficient flexibility to cope with peaks/troughs in activity
- High quality and cost effective
- Ability to cope with projected future activity levels

The Review Board is composed of senior representatives drawn from the profession and the NHS system, providers and commissioners and includes lay representation.

The Board will evaluate the effectiveness of the current NORS provision and make recommendations, with due regard to advances in technology, in a report to ensure the future provision of a quality service across the UK.

Remit

The Board's remit is to drive and steer the review - adhering to agreed timescales for delivery, - bringing in expert knowledge and advice as necessary, in order to make recommendations with due consideration of the overall impact of any suggested changes, their interdependencies and associated collateral effects.

To achieve these objectives the board will:

- provide strategic oversight and governance to the review and its outputs;
- ensure appropriate experts are consulted and data used to inform the review;
- define the areas for discussion, the processes to be scrutinised and the overall coverage;
- commission working "subgroups" as required to undertake detailed work on specific areas for exploration;
- deliver an in-depth report on the current circumstances, where areas for improvement have been identified and what recommendations the review advises NHSBT make in terms of service reform;
- Take a broad view of the service and consider it as part of a larger system.

Summary of the discussion

This section is about what delegates said at the event. They gave the Review some clear messages.

Points from the Open Session

In the open session, delegates were asked to consider the key challenges and main priorities for improvement.

The Donation Process

There were a number of comments that the length of the donation process is getting longer and that donors are being lost due to this, as families either refuse on the length of time, or withdraw consent because of the time taken to proceed.

There was concern that as donation increases, if the structure of the teams is not sufficiently flexible to meet the needs of the donors, then there will be more losses due to time delays.

NORS Structure

The process discussion led to comments about the retrieval zones and the way in which teams are structured and the allocation of donors.

The zonal arrangements and also decisions about donors after circulatory death (DCD) attendance were considered vital, if the service is to cope with increased donor number targets and the unpredictable nature of donation.

Donation and the Transplantation Pathway

A number of related comments were made around the need for the NORS process and statistics to focus on transplants rather than on donation. A view was expressed that in the work to reach the 50% target, the focus has been on donor numbers and that has meant that some very marginal potentials were being attended, which has impacted on NORS costs/times with little benefit.

It was felt that the statistics that NHSBT produce and the targets teams work to meet were focused on donation numbers, without considering the transplantation outcomes. Several expressed the view that they need refocusing on transplant outcomes, so the service aims for higher quality organs and not just more donors.

Aside from this broader issue, it was felt that donor activity should, at least, be measured by organs retrieved, not by attendance, to get a more accurate picture of the teams work.

Triage and Non Proceeding Donors

Views were expressed that there was a need for a future service to use an effective system of donor triage, to ensure that only donors with real potential to donate are attended.

CHALLENGE EVENTS

The Review is conducting a series of Challenge Events in order to improve and refine its approach and recommendations.

Challenge events are not consultation in the usual sense. As an independently Chaired Review, we don't have to consult formally on our recommendations, since they are not binding.

Challenge events are best seen as a form of careful listening.

Challenge events bring together a representative group of people who have some form of expertise and or interest in the matters under review.

At each event, we will share the current state of thinking within the Review: a summary of our methods, any evidence we have received, our provisional thinking or findings, and the emerging themes that will form the raw material for our recommendations in due course. We will then invite comment and challenge.

The responses we receive will contribute significantly to the evidence base, relevance and feasibility of the Review's findings and recommendations.

The need to reduce the number of non-proceeding DCD donors was raised a number of times. It was raised both as a barrier to effective working of the teams and as a significant cost and time pressure, where teams were out on donors who were unlikely to proceed, resulting in non-zonal colleagues having to attend donors after brain-dead (DBD) / more likely donors. This impacts on overall service costs and availability for real potential. A view was expressed by some participants, that DCD could be handled by local units, rather than NORS teams, who should only attend DBD's.

The view was expressed both through the consideration of triage and a repeated statement that the focus needs to be on transplantable, high quality organs, rather than just increasing donor numbers. DCD were also considered to increase donation times with a subsequent impact on the donor family.

There were comments that some DCD's could proceed to DBD donation and could there be a financial benefit offered to units to facilitate this.

Quality

There were a number of linked comments about optimal organs being retrieved and the outcome of transplants needing to be the focus of the service. There was some feeling that in the plan to get as many organs as possible for transplant we may be transplanting less effective grafts.

Some felt that many issues around Organ damage/poor perfusion etc. are not being formally reported and recorded. There was considered to be no room in a modern service for the informal

chats with colleagues that have reportedly taken place in the past. Need to continue to firm up the process (separate from the Review) and ensure that all quality issues are recorded, so they can be considered and addressed and the service improve moving forward.

The barriers between different NORS teams need to be broken down. The teams need to develop confidence in the other teams, and commissioners need to work with the teams where there are issues. Other specialist groups within the sector also need to work to break down barriers and enhance working together.

Commissioning and Funding

A variety of comments around commissioning and funding were received. There were many calls for NHSBT to work more closely with NHS England and the National Health Authorities to make sure any changes to be implemented across the UK were adequately funded, with due consideration of the impact on transplant services. The view that commitments needed to be made to fund any increases in donation activity was made several times and reflected a concern that if activity increases, the service will be stretched to a point where quality is impacted. There were also a number of comments that NHSBT needed to fund Scouts and related activity designed to improve the service.

"NORS is currently ORS – the National has dropped off." Views were expressed that commissioning for retrieval at present does not cover all costs e.g.: Scouts and Organ Care System. It was felt that commissioning should reflect the full work of the NORS teams and elements like the number of out of zone retrievals should also be a factor in funding. Where workforce was referenced it was in relation to funding and ensuring the correct workforce can be financed moving forward.

There was a recurring comment throughout the meeting that NHSBT is focusing through TOT2020 and its commissioning on increasing organ donation numbers, but that does not necessarily correlate to quality transplants. A view was expressed that the focus of NORS needs to shift to ensuring good transplants take place.

In terms of 'Value for Money', it was agreed there was a need for the review to consider how to obtain best value, while taking into account the variable costs impacting on different teams e.g. the need to fly to donors. Broadly, it was considered vital that commissioning should be used to encourage a 'truly national system'.

A Desirable Service

"High Volume. High Quality. Good Outcomes."

Training and Development

Standard of training for the retrieval teams and lead surgeons impacts on the retrieval and transplant outcomes. The current set up has a professional membership and skills bases, but it is hard to recruit to and difficult to cover fluctuating activity. There is a need for effective training to be in place to upskill members and allow for professional development, to make the job attractive, with better career planning and opportunities

Competency Framework: a formal and accredited competency framework for retrieval should be instigated, which would formalise good practice and standards and reduce organ damage.

Logistics

It was suggested that NORS teams should be mustered by a central planning unit that can make best use of resources and it was felt that consideration should also be given to centralised transport.

Radical thinking

The review team were asked how radical the recommendations could be, in response to the confirmation that the review currently had 'no constraints' on its thinking the following comments were made:

Could there be the potential to move to system of retrieval centres, where donors are taken for the retrieval process to take place, then afterwards moved back to their home hospital/funeral director etc?

Would it be possible to concentrate retrieval team expertise into fewer teams with wider responsibility for all retrieval activity on behalf of transplantation units?

Main Priorities for Improvement

- Closer working with NHS England and the other National Health Authorities;
- Donation and Transplantation pathway needs to be more joined up;
- Reduce length of the donation process;
- There is an acceptance that the capacity and structure of the service is an important area to address moving forward. Use the structure to ensure greater equity of retrieval workload for NORS teams;
- Triage, so more DCD attendances result in donation and transplants;
- Review of current contractual arrangements and potential for economies of scale;
- Central NORS despatch;
- Drive forward innovation EVLP/OCS/Scouts. Build in cost of new technologies;
- Better trust and communication between retrieval and transplanting teams;
- The Review should be radical in its thinking and be prepared to go back to the drawing board if that's what it takes to get the system ready for the future.

Inevitably, a number of the issues raised fell outside of the remit of the Review. It was, however, good to hear these points and it will be important that the Review is conducted with an understanding and appreciation of some of the wider issues.

Points made that are out of the scope of the review

- Equity of access to organs including allocation schemes Several comments that in Cardio there needs to be greater equity of access to organs for all potential recipients
- Improve donor family experience including timescales for retrieval. Increase consent rates
- Organ Acceptance
- Organ Utilisation Need to make sure that decisions to accept or reject organs are reasonable and appropriate. Different centres make different decisions and questions were raised as to the motives that may drive those decisions. Several tables questioned if a central acceptance scheme were possible.

Breakout sessions

In the afternoon, three breakout sessions were held. In each of the break out groups delegates were asked to identify issues, opportunities for improvement and potential areas for recommendation around the given topic area. The participants then fed back to the main meeting the key messages and comments, for further discussion in a plenary session.

Workforce

In the workforce workstream breakout session, delegates discussed issues relating to the variability across the current UK service and the minimum workforce requirements.

Issues

The different retrieval requirements of DBD and DCD donors, was regarded as a key area for consideration. Allocation was also seen as having an effect on NORS teams, as some teams may feel greater ownership if they see their own patients benefit. Additionally, future technology in organ retrieval was considered to be an issue.

Specific concerns were identified around the sustainability of the service and the need for a well-trained and motivated workforce, with succession planning. This led to discussion of issues around the recruitment, retention and training of staff and the potential need for a Certification of Competency. Travel Times and the EU Working Time Directive were also identified as particular workforce issues.

Opportunities for Improvement

Donor optimisation becoming a part of NORS; Communication: inter team, between teams and with the recipient side; the process of calling out/mobilising teams; the synchronising of handover/notes and knowledge between NORS teams and the Triage of Donors; were all seen as areas where improvements could be made.

Areas for Recommendation

In considering areas for recommendation, it was felt that a good starting point would be to give specific attention to what was needed from the workforce to get transplantable organs. Additionally; multi organ teams; whether the NORS service should be Consultant led; the need for NORS to include specialist services - such as intestinal retrieval; model ROTAs and the wider team necessary to support retrieval, were all considered to be potential areas for recommendation

Capacity

In the capacity workstream breakout session delegates discussed the current service configuration and potential delivery models.

Issues

There was discussion from the Abdominal NORS representatives (Liver Surgeons) that they are being called out to DCD donors where they feel the livers are of lesser quality and while at a DCD they could miss the chance to retrieve a DBD Liver, which was of much better quality. They questioned whether the drive to increase donation was leading to attendance at donors where organs would not be retrieved, or may not, if retrieved, be transplanted.

DCD Kidneys: extended criteria kidneys were considered to be leading to reduced quality transplants. There was a query as to whether the need to increase donations is being considered above the need for quality organs. There was

an argument from some participants that transplanting lower quality kidneys, with a shorter half-life, was a way of massaging the transplant waiting list, as those transplanted will be back on the waiting list in a few years.

Cardiothoracic NORS team members indicated that they felt the hours they worked are different to the number of donors attended; this caused them to dispute the statistics around the % time cardiothoracic teams are out.

There were also conflicting opinions. Some thought the focus should be on transplantation rates not just donation rates - only retrieve what will be used; where as others felt the issue was more about Organ Utilisation and that the service should retrieve all available organs and that the system should work towards as many organs being accepted and used as possible.

Mode of transport chosen was considered an issue e.g. if a flight was required by NORS for retrieval, then donation would take longer and be more expensive, this should be considered when looking at NORS team costs.

Opportunities for Improvement

Central coordination of teams was seen as a key opportunity for improvement.

The group also discussed relaxing the one hour muster time. It was considered that the rule had been embedded at the start of the NORS service, to convince donating hospitals and Consultants that donation was being taken seriously. With this trust now in place, there could be improvements if the muster rule were relaxed, to allow a nearby NORS team to muster later, perhaps after finishing another donation, rather than immediately mustering a team that were further away. The group felt that some flexibility should be built into the system to achieve the best outcome.

Liver surgeons indicated they would prefer to be able to give preference to a DBD donor, even if they had been called to an earlier DCD, so they could retrieve the liver. Regarding DCD Kidney Only retrieval, it was considered to be possible for local units to retrieve in scenarios where it is clear there is a kidney only donation, which would leave full NORS teams available to retrieve multi-organ donation elsewhere.

Areas for Recommendation

Considering areas for recommendation; it was felt that the zonal arrangements needed to be looked at. The question of the number of NORS teams was raised - do we need more or less teams? With the predicted activity increase, some felt there was scope for another abdominal centre, which led to further discussion around whether it would be more cost-effective for some existing centres to have more than one team

The concept of Combined Cardiothoracic/Abdominal teams was also considered worth scoping - Scottish participants felt this worked well there; however, some Cardio participants considered this would impact on cardio organ quality. Surgical rotation through a central OPO to provide NORS surgeons and give the role a place in a medical career path was also considered worth exploring.

Thinking more broadly, delegates felt consideration should be given to - if we were starting from scratch, where would we put teams?

Commissioning

In the commissioning workstream break out session the delegates discussed performance criteria and funding models.

Issues

It was felt that Commissioning should focus on patient outcomes, quality and donor/donor family experience. Too much attention was given to process, compared to wider NHS commissioning. The data collection requirements

seemed onerous for the budget size – it is disproportionate. Advisory groups should focus on outcomes, but they're not linked to the money, so the set up within NHSBT may not be right.

Service isn't standardised – teams seem to have different retrieval criteria. There is a disconnection between the management and clinicians of the NORS teams. Commissioners should visit the providers and understand their issues and concerns. NHSBT doesn't traditionally have a commissioning background and there were questions as to whether there were enough people within NHSBT commissioning to manage the growing activity.

Activity is increasing but funding is static. Delegates felt this unsustainable if NORS is to hit TOT2020 targets. Is it even possible to fund the service from the current pot? If not, a bigger discussion needs to happen with NHS England. More funding would need to come from them to fund transplant. Could National commissioning of the whole pathway be an option?

Opportunities for Improvement

A need for the emphasis to shift from NORS winning the trust of ICU's to ensuring that high quality organs are retrieved. NHSBT can ensure the NORS teams get in the one room, but once there it's the teams that can drive improvements.

Felt it was good that local commissioners attend SORT's CRM and that this would be useful for the other teams.

Suggestion that scouts should be commissioned as part of abdominal teams.

Areas for Recommendation

Participants felt that a lighter touch, outcomes based commissioning model should be considered. They also thought that NHS England and NHSBT's budgets should be looked at together, as the services in the trusts are interlinked, so the commissioning arrangement should be also. NHSBT and NHS England need to make intentions more explicit and any separation of retrieval tariff needs to include overheads and back office.

The advisory groups need to have more than one management representative. All the centres work differently so management from each should be represented.

Stronger relationships between NHSBT and all teams, so that local and national issues can be shared, before they become problematic.

Conclusion

The establishment of a National Organ Retrieval Service has clearly contributed to the increase in donor rates. Throughout this challenge event, we also heard many other positive comments about NORS. Unlike the old system, someone is allocated for organ retrieval every day. The current system, with certain exceptions, prevents multiple teams attending a donor. Some National standards and competencies have been established and are being maintained. Relationships have been built between members of the NORS teams and this working together, over the years, has proved beneficial when facilitating a donation and there is equity of access to donors for all transplant units.

However, retrieval standards are not considered to be uniform across the NORS teams. There appears to be issues of trust between some transplant centres. DCD retrievals have to be facilitated. Not all centres are consultant led and the small bowel team is considered as an example of where, despite the NORS system, multi team donor attendance is still required. Additionally, Cardiothoracic retrieval is sometimes considered a 'bolt on' and is not perceived as a 24hr service and there are sometimes delays in facilitating donations while waiting for cardiothoracic teams to attend.

Clearly there are areas for improvement and the Review Team is grateful for the generous way in which delegates gave up their time and shared their wisdom and experience with them as they work towards their recommendations.

Further engagement

The Review's Workstreams will now progress with their individual tasks, taking into account the thoughts and ideas expressed at the event.

The Review Team are also undertaking a programme of visits to NORS teams across the UK.

A further Stakeholder Event is scheduled for 16th October. To register for this event, please contact: lisa.drakett@nhsbt.nhs.uk

Stakeholders are also invited to send comments direct to the Review team, emailing: daniel.gosling@nhs.net