

SCOTTISH GOVERNMENT HEALTH AND SOCIAL CARE DIRECTORATES
Minutes of the Scottish Donation and Transplant Group Meeting Held on
Wednesday 04 September 2019,
Atlantic Quay, Glasgow

Present:

Iain Macleod	Joint Chair and Clinical Adviser for Organ Donation in Scotland
John Casey	Joint Chair and Clinical Adviser for Transplantation in Scotland
Charles Wallis	Regional Clinical Lead for Organ Donation
Claire Williment	Head of Deemed Consent Legislation Implementation, NHSBT
Gabriel Oniscu	Consultant Transplant Surgeon and Clinical Director, Edinburgh Transplant Unit
Heather Maxwell	Consultant Paediatric Nephrologist
Jen Lumsdaine	Living Donor Co-ordinator
Keith Rigg	NHSBT Board Member
Lynne Ayton	Head of Operations, Golden Jubilee National Hospital
Roseanne McDonald	Programme Associate Director: Nursing and Quality Adviser, National Services Division
Sharon Zahra	Clinical Lead, Tissues and Cells, SNBTS
Neil Healy	Senior Nurse for Tissue Services, SNBTS
Stephen Kirkham	Patient Representative
Susan Hannah	Regional Manager (Scotland), NHSBT
Sam Baker	Donation Team Leader, Scottish Government (SG)
Fern Morris	Policy Manager Implementation Team, SG
Linda White	Policy Manager, SG

Apologies:

Alastair Innes	Consultant Respiratory Physician
Andrew Walls	Organ Donation Committee Regional Chair, NHS Dumfries & Galloway
Ann-Margaret Little	Consultant Clinical Scientist, NHS Greater Glasgow and Clyde
Anthony Clarkson	Director ODT, NHSBT
Anthony Warrens	HTA
David Turner	Consultant Clinical Scientist, SNBTS
Jessica Porter	Head of Regulation, HTA
John Forsythe	Associate Medical Director ODT, NHSBT
Neal Padmanabhan	Consultant Nephrologist, NHS Greater Glasgow & Clyde
Lesley Ross	Patient Representative
Marie Gardner	Service Manager, NHS Lothian
Marc Clancy	Consultant Surgeon, NHS Greater Glasgow & Clyde
Andy Bathgate	Consultant Hepatologist, NHS Lothian
Stephen Wigmore	President, British Transplantation Society
Stephen Cole	Scottish Intensive Care Society Representative
Nawwar Al-Attar	Consultant Transplant Surgeon, Golden Jubilee National Hospital
David Walbaum	Consultant Renal Physician, Aberdeen Royal Infirmary

In attendance:

David McIlhinney	Policy Officer, SG
Suzanne Mendes (Observer)	Programme Manager, NSD

Item 1. Welcome and Apologies

1. Dr Macleod chaired the meeting and welcomed members. In particular he welcomed Mr Gabriel Oniscu to his first meeting of the group in his role as Clinical Director of the Edinburgh Transplant Unit following Jim Powell's move to a new role. He also introduced Susan Hannah, NHSBT Regional Manager for Scotland, to her first meeting of the group, and Suzanne Mendes from National Service Division as an observer.
2. He advised the group that unfortunately Gill Hollis, patient representative, had resigned from the group on the grounds of ill-health and that Claire Williment was attending the meeting on behalf of John Forsythe, NHSBT.

Item 2. Minutes of Previous Meeting – 24 April 2019

3. The previous minutes were accepted as an accurate record of the meeting with some minor grammatical amendments to be taken on board.

Item 3. Human Tissue Authorisation (Scotland) Act 2019

Item 3.1. Implementation Update

4. Ms Morris advised that the Human Tissue (Authorisation) (Scotland) Act 2019 gained Royal Assent in July. The Act was due to be implemented in autumn 2020. A number of implementation workstreams had been set up and the workstream leads were currently meeting on a fortnightly basis to discuss their progress. A Programme Board would oversee implementation and would meet for the first time on 30 September 2019.
5. The Scottish Government marketing team were leading on a public information campaign to raise awareness of the law change during the lead up to implementation. A Public Information Reference Group, with a membership of key stakeholders, had been established. It was agreed that the marketing team would ensure NHSBT had plenty of notice before any key awareness raising initiatives so they could ensure sufficient staff were in place to manage additional calls.

Item 3.2. Chief Medical Officer Guidance on Pre-Death Procedures

6. Ms Baker highlighted that the Human Tissue (Authorisation) (Scotland) Act 2019 would bring significant changes to pre-death procedures and the existing CMO guidance was currently being updated to reflect these. She advised that a draft of the guidance would be shared with ICU consultants in due course.

7. It was noted that there is a duty in the Act to raise awareness of pre-death procedures with the general public in order to clearly explain them. A public consultation on the draft regulations would also be undertaken.
8. Discussion ensued around the need for the list of Type A procedures to be an inclusive list as medicine continues to evolve. It was noted that the proposed pre-death procedure list would be monitored on an ongoing basis with updates being made to secondary legislation in the future if appropriate. It was agreed that SDTG should have a role in future in discussing any proposals for additions or other amendments to the regulations.

Item 4. Donation where the Potential Donor is Pregnant

9. Ms Baker advised that the Scottish Government had been considering, with NHSBT, whether deceased organ donation could take place in circumstances where the potential donor was pregnant. It was noted that the number of instances of potential donors who were pregnant is very small.
10. In 2016, the Chief Medical Officer had indicated that due to legal/ethical complexities, she would support donation where a donor was pregnant, but that it was for NHSBT and NHS Boards to take their own legal advice on this in relation to Scots law.
11. Advice from the BMA's Medical Ethics Committee had now indicated that, from an ethical perspective, it would be acceptable to proceed with organ donation by pregnant donors via donation after circulatory death (DCD) where the foetus was not viable (in other words could not survive). However donation after brain death (DBD) would require a view from the Courts before it could be considered.
12. In light of this advice, NHSBT proposed to develop guidance with the Faculty of Intensive Care Medicine to permit DCD donation by pregnant donors in future.
13. It was reiterated that the decision on withdrawal of treatment from a pregnant patient would be for the NHS Scotland staff in the donating hospital, with ICU clinicians taking advice from the appropriate specialists, such as obstetricians and/or neonatologists and, as appropriate, their own legal advisers, to reach a view on whether it was both appropriate and lawful to withdraw treatment from a pregnant woman in each case.
14. The group was content with NHSBT's proposals for UK guidance on this matter being issued, but emphasised that the Scottish Government's position should be confirmed and communicated to retrieval surgeons to provide reassurance.
15. Ms Baker agreed to follow up on this and confirm the Scottish Government's position as soon as possible.

ACTION – S Baker to confirm the Scottish's Government's position and to ensure this information is communicated to the relevant individuals and groups

Item 5. Organ Donation Performance and Update (Scotland)

16. Ms Hannah provided an update on organ donation performance and trends in Scotland and highlighted a drop in deceased donor numbers over the last five years.
17. Fewer deaths in the appropriate circumstances and lower eligibility had been cited as the main reasons. There had been eight family overrides in the period April – June 2019 where the patient had been on the ODR and a spike in opt outs during the same period, which was in line with the UK trend for opt outs.
18. The length of the donation process was discussed as an important factor in family overrides as well as occasional delays in retrieval teams arriving at the donor hospital and a number of other reasons for delays. It was noted that there were complexities linked to planned and unplanned delays which can contribute to the length of the donation process.
19. It was agreed that further data should be gathered if possible to clarify the current situation, including length and impact of each type of delay to help identify where improvements could be made and to help manage family expectations around the length of process.
20. Ms Hannah also confirmed that NHSBT was finishing backfilling the Specialist Requesters' post and that the team was on track to commence implementation of the specialist requester model in Scotland in January 2020. She also noted that the new animation clip which was being shown to potential donors' families was being well received by families.

Item 6. A Donation and Transplantation Plan for Scotland 2013 – 2020 – Implementation Plan

Item 6.1. Position Update

21. Dr Macleod noted that NHS Grampian was now inviting NHS Orkney and NHS Shetland to join its Organ Donation Committee. He agreed to write to NHS Grampian and NHS Highland to ask them to confirm that the three Island Boards had now agreed to join a Committee.
22. It was emphasised that people that live in the Island's should have the same information and education about donation as other areas.

ACTION – SDTG Chairs to write to NHS Grampian and NHS Highland Organ Donation Committee Chairs

Item 6.2. Living Donation Update

23. Ms Lumsdaine informed the group that the link nephrologists were continuing with their project to capture the transplant decision for all patients in Scotland approaching end stage renal failure. Around 960 patients had been identified in the June 2019 survey as having a recorded transplant decision.
24. The Renal Education and Choices at Home pilot continued to show positive results in encouraging open discussion within the family home about treatment options. As part of an exercise to identify where living kidney donors

hear about living donation, a recent survey of 100 living donors identified the media as being a particularly important channel in engaging altruistic donors. Family and friends provided the most awareness about directed donation.

25. The results also showed that 84% of altruistic donors have been blood donors, compared with 36% of directed donors so this showed the value of continuing to use SNBTS to support awareness raising.

Item 6.3. Organ Donation Week 2019 (1 – 8 September)

26. Mrs White reported that the Minister for Public Health, Sport and Wellbeing launched Organ Donation Week in Scotland with a visit to Aberdeen and met a 10 year old recipient of a heart valve transplant, which gained significant press coverage. Other activities continued throughout the week with much enthusiasm and support from Specialist Nurses in Organ Donation and local organisations to help light up buildings green and to encourage people to think about their organ and tissue donation decision and share this with loved ones.

Item 7. Post 2020 Strategies/Plans - Update on Progress

Item 7.1. Scottish Government

27. Ms Baker provided the group with an overview and presentation which outlined the proposed key priorities for the Scottish post 2020 plan. These had already been discussed at the previous meeting. She went on to advise that it was the intention that the Scottish plan would span 10 years from 2020, which was in line with the timescale proposed for the post 2020 UK Strategy.
28. The focus of the Scottish plan was on actions or recommendations which could add value to help increase donation and transplantation or improve the outcomes from transplants.
29. The Scottish plan would have a key focus on novel technologies, such as Normothermic Regional Perfusion (NRP) for livers and would also consider the broader use of NRP for other organs, where appropriate.
30. Mr Oniscu advised that he had obtained NRP data for other organs, such as kidneys, and would be willing to share this information and present it at a future meeting.
31. It was also noted that DCD heart technology was already ready to be used in Scotland for DCD heart retrievals and the evidence and technology available should evolve significantly in the next few years. It was also suggested that regenerative medicine should also be highlighted in the plan.
32. It was noted that funding opportunities for research should be considered further as part of the Scottish plan.
33. Aftercare post-transplant, in particular psychology, was raised as a concern, with the lack of psychologists in NHS Boards being a particular issue. Ms Baker agreed that the Scottish Government would follow this up with mental health colleagues in the Scottish Government.

34. It was highlighted that NSD intended to hold focus groups with recipients to explore aftercare in relation to physical and mental health in order to get a better understanding of patient views on this area to help inform their plan. The Scottish Government would also be involved in these focus groups.
35. Discussion ensued around the 10 year timescale for the Scottish plan. It was agreed that there was a need to consider the long term and to be aspirational, but to also focus on short term aims. It was suggested that setting out key milestones against the proposed actions would be a positive way to visualise the balance between long term aspirations and planning against the shorter term aims.

ACTION: Mr Oniscu to present NRP data for other organs at a future meeting

ACTION: S Baker/L White to enquire whether there are any plans for additional resource to support psychology for patients

Item 7.2. National Services Division

36. Ms McDonald reported that the post 2020 NSD plan would focus on commissioning transplantation as well as the impact of donation on transplantation. A short life working group and wider reference group had been established to oversee the development of the NSD commissioning plan.

Item 7.3. Post 2020 UK Strategy

37. Ms Williment advised that NHSBT had arranged a number of events across the UK to seek views from stakeholders on the initial proposals and strategic themes for the UK Strategy which included diversity, living and deceased donation, organ reconditioning and research. The Scottish event would be held on 3 October 2019 in Edinburgh.

Item 8. AOCB

Item 8.1. Major Review of the Scottish National Advanced Heart Failure Service

38. Ms McDonald advised that the Review was expected to submit their final report to the National Specialist Services Committee in late November/early December 2019.
39. There were a number of challenges facing this service, including the need to improve utilisation rates in order to help reduce waiting times and using hearts from marginal donors, particularly where geography is a challenge. However the use of perfusion technology for DCD hearts could potentially help resolve this issue longer term.

Item 8.2. Normothermic Regional Perfusion for Livers – update

40. Ms Baker reported that the Scottish Government and the Welsh Government had already agreed to fund their share of the UK rollout of NRP for livers. The UK Government was still to confirm their position. In the interim, Scotland had

received confirmation from NHSBT that they would continue to fund the Edinburgh unit for NRP for the rest of the 2018-19 financial year.

41. Ms Williment reported that the Department of Health and Social Care was very supportive of NRP, but currently had significant financial challenges in relation to the Spending Review.
42. The group agreed that NRP had a lot of potential to increase organ utilisation and was keen to see NRP retrievals funded longer term across the UK.

Item 8.3. DCD Hearts – Update

43. Ms Ayton confirmed that NHSBT had confirmed that the Golden Jubilee National Hospital would be part of the consortium of retrieval teams funded to carry out DCD heart retrievals over the three year period of NHSBT/NHS England funding for Organ Care System consumables. The group agreed that this was a very positive development.

Item 8.4. Tissue Donation

44. Dr Zahra suggested that, in order to help further raise the profile of tissue donation, Organ Donation Week be renamed as Organ and Tissue Donation Week going forward. She highlighted that as tissue donation was part of deemed authorisation under the new law, it should have dual recognition and have a similar profile to organ donation. It was highlighted that there was a need to manage messaging around the new law to ensure the general public fully understands their choices and that people are not confused. Marketing colleagues in the Scottish Government were taking forward work around messaging and their forthcoming Omnibus survey would help to identify the most appropriate language that should be used in future communications in relation to organ and tissue donation.
45. It was agreed that this matter should be considered by Scottish Government communication experts and their advice sought on a way forward with this.
46. It was also suggested that any renaming of Organ Donation Week should be considered as part of the post 2020 Scottish plan. Donation and Transplantation Week was also suggested as a potential rebrand name for consideration.

ACTION: L White to arrange a meeting with SNBTS, marketing colleagues and SG external PR specialists to discuss in further detail.

47. Dr Zahra commented that it would be helpful if Tissue Donor Co-ordinators in Scotland had direct access to the Organ Donor Register to help avoid risk of errors due to them needing to manually write down details given over the phone. It was agreed that Dr Zahra and the NHSBT ODR team should discuss this out with the meeting.

Date of next meeting

The next meeting would be held on the 18 December 2019 between 14.00 – 16.30 at St Andrew's House, Regent Road, Edinburgh, EH1 3DG.