



The DonateLife State Medical Directors' Committee

Communiqué
24 June 2010

The second meeting of the DonateLife State Medical Directors' Committee was held on Thursday 24 June 2010.

DonateLife is an Australia wide network of organ and tissue donation agencies and hospital based staff dedicated to organ and tissue donation. Under the leadership of the Organ and Tissue Authority, State Medical Directors (SMDs) in every state and territory are responsible for delivery of the national reform program in their respective jurisdictions.

The DonateLife State Medical Directors' Committee has been established by the acting Chief Executive Officer (CEO) of the Organ and Tissue Authority as a governance committee to consider and make recommendations to the Authority in respect of the strategic priorities, clinical and data governance, planning and leadership of the DonateLife Network, and the implementation at a state-based level of the World's Best Practice Approach National Reform Package on Organ and Tissue Donation for Transplantation.

The DonateLife State Medical Directors' Committee comprises the CEO (Chair), the National Medical Director (NMD) and the SMDs of each State and Territory, including:

Ms Liz Cain (A/g CEO)
Dr Gerry O'Callaghan (NMD)
Dr Jonathan Gillis (NSW)
Dr Imogen Mitchell (ACT)
Dr Helen Opdam (Vic)
Dr Phillip Sargent (Qld)
Dr Dianne Stephens (NT)
Dr Sally Tideman (SA)
Dr Andrew Turner (Tas)
Dr Kevin Yuen (WA)

Reflecting outcomes of the first meeting of the DonateLife State Medical Director's Committee, the second meeting was also attended by senior officials from the State and Territory Health Departments as well as the Department of Health and Ageing. The addition of officials from all health departments ensures that the efforts of the DonateLife staff reflect state and Australian government policies and processes, that legislative and funding implications are well understood by relevant departments and promotes a nationally consistent and coordinated approach to increasing organ donor rates in Australia.



The Hon Mark Butler MP, Parliamentary Secretary to the Australian Government's Minister for Health and Ageing attended part of the meeting to reiterate the Australian Government's commitment to establish a World's Best Practice Approach to Organ and Tissue Donation for Transplantation to address the shortage of organ and tissue donations in Australia. Discussion centred around the Australian Government's well researched reform plan for increasing organ donation rates based on proven best practice which includes funding:

- 160 doctors and nurses in 76 key hospitals throughout Australia to provide specialist organ and tissue donation clinicians to lead an increase in clinical staff education and awareness and increase organ and tissue donation rates in hospitals; and
- 59 staff in organ and tissue donation agencies around Australia to support the specialist clinical staff through the provision of organ and tissue donation coordination services.

The Parliamentary Secretary highlighted the important role of the DonateLife State Medical Directors in each state and territory who lead their staff as the front line of the Australian Government's reform agenda. Through these staff it should be possible for every potential donor in each of the 76 hospitals to be identified and the families of potential donors be well supported, lifting Australia's rate of organ and tissue donation. The employment of these staff lays a strong foundation for system reform within the 76 hospitals.

The foundation within hospitals is the first of two key elements of reform. The second relates to improving the rate at which Australian's consent to donation of organs by their loved ones. Although the majority of Australians support organ and tissue donation, family consent for donation to progress is less than 60 percent. To address this, the Authority is leading on delivering an integrated and coordinated public education and awareness program, in cooperation with Non-Government Organisations (NGOs) and the DonateLife sector.

The Parliamentary Secretary will attend a future meeting of the Committee for more detailed discussion.

Progress with the National Reform Agenda

The DonateLife SMD Committee carefully reviewed progress against each of the nine Measures which comprise the Australian Government's reform agenda. The Committee focussed particularly on establishing the performance framework against which progress by the Authority and each State and Territory would be measured, and agreed to provide final comments on Annexures A – F of funding agreements proposed for the reform agenda by 12 July 2010.

The Committee was pleased to note that all nine Measures are on track.

Measure 1: A new national approach and system – a national Authority and network of organ and tissue donation agencies

The intent of Measure 1 is to increase organ and tissue donation rates in Australia by establishing for the first time in Australia, a nationally coordinated approach to organ and tissue donation and retrieval based on world's best practice models. The Organ and Tissue Authority has been established as a new, independent authority to provide national leadership to the organ and tissue sector and to drive, implement and monitor national reform initiatives and programs. In addition, Organ and Tissue Agencies have been established in each State and Territory, headed by a State or Territory Medical Director and funded by the Authority to coordinate, oversee, lead and report to the Authority on actions taken in each state and territory under the reform program.

The key elements in Measure 1 are:

- The establishment of the Authority to oversee the implementation of the Australian Government's national strategy for organ and tissue donation.

The Committee noted the new structure of the Authority presented by the a/g CEO to take effect from 1 July 2010 which will provide enhanced capacity within the Authority to deliver the Australian Government's reform agenda and support the DonateLife Network, particularly the SMDs. A copy of the new structure is at Attachment A.

The Committee also noted the National Strategy prepared by the Authority in consultation with stakeholders including SMDs and the Australian Organ and Tissue Donation and Transplantation Advisory Council. The National Strategy is an important document since it presents, clearly and simply, the strategic breakthrough issues and sets clear targets for these: 100% of hospitals identify 100% of potential donors, 100% of potential donor families are supported in making informed decisions, 80% of families consent to the organ and/or tissue donation of their loved one, 40% of families initiate discussions in hospitals about organ and tissue donation, and the Authority retains high quality staff and effectively implements the Government's reform agenda through the following performance indicators:

1. The Authority complies with all relevant legislation, including the Public Service Act and the Financial Management Act; and
2. The Authority maintains an employee retention rate of 85%.

The Committee noted that targets such as 100% of hospitals identify 100% of potential donors are achievable, if the reforms are effectively implemented.

The Committee noted that the 2nd Annual Report of the Authority is due to be tabled by 31 October 2010. The Committee supported the A/g CEO's request that each jurisdiction provide input into the Annual Report as an enhancement to the process by which the first report was prepared, and endorsed the template for jurisdictional input into the 2nd Report. The Committee agreed that input would be provided to the

Authority by 31 July 2010. The Committee also endorsed the Authority's outline of the 2nd Annual Report.

- A national data set which reports publicly on how the national reforms are progressing.

Report Card

The Committee endorsed the proposal that the Authority produce a National Report Card which will contain statistical information and a narrative about the statistics, highlighting key information about donation rates and other performance information. The Committee agreed the important role that the data and narrative on organ donation rates, presented in a simple and concise manner, has in informing the Australian community of the facts in relation to organ donation. The Committee also endorsed the Authority's plan to enhance the National Report Card to include additional information about tissue donation rates.

The Committee considered a draft of the National Report Card prepared by the Authority, endorsed the approach and agreed to provide comments on the draft by end June 2010, noting that the Authority intends to release the first of the National Report Cards in early July 2010, reporting on the year to date.

The Committee recommended that the Authority release the National Report Card quarterly.

Electronic Donor Record

The Committee discussed issues related to the progress of the development of an electronic donor record.

The Committee was advised that while the former CEO of the Authority had made progress with establishing an electronic donor record (DONORtrak), a detailed business case had not been provided supporting (a) the development of an electronic donor record or (b) DONORtrak specifically. The Committee advised that to enable jurisdictions to make a decision about the priority of this work relative to all other work (and expenditure) the Authority needed to develop and present a detailed business case for an electronic donor record.

The Committee noted the A/g CEO's concern that work progressed by the former CEO had now raised expectations amongst some stakeholders that an electronic donor record (possibly specifically DONORtrak) would be implemented. The Committee agreed that notwithstanding this, the Authority must develop a business case regarding the development of an electronic donor record. The draft business case will be circulated for input prior to seeking subsequent endorsements as necessary. The Committee agreed to proactively communicate its decisions regarding an electronic donor record to State and Territory stakeholders and to manage any local concerns and that the Authority would need to manage any concerns raised by its work to date.

The Committee agreed that the A/g CEO would ensure a business case would be prepared for both an electronic donor record and the redesign of the portal.

The Authority agreed to provide advice to all jurisdictions about the applicability of the Freedom of Information legislation to personal and private data held by or on behalf of the Authority.

Death Audit

The Committee recommitted to ensuring that the Death Audit, which will provide valuable statistical information about processes within individual hospitals to identify potential donors and manage these proactively, would be populated in a nationally consistent way across all participating hospitals from 1 July 2010.

The A/g CEO distributed to each jurisdiction its information on the identification and consent data collected from all participating hospitals through the death audit and the Authority's portal from January – May 2010, noting that it appeared that all jurisdictions have gaps in the data collected to date. Jurisdictions agreed to review the material provided and work with the Authority to clean and complete this data as soon as possible. However, several members noted that the information provided was not consistent with the data that was entered into the system. It was suggested by committee members that this issue also needs to be investigated. The A/g CEO acknowledged the work already underway in a number of jurisdictions in relation to ensuring a complete data set, thanked jurisdictions for their efforts and will seek specific advice regarding dates for this process to be complete.

The committee advised the A/g CEO that there were a number of concerns regarding the portal and its ability to accurately report or maintain the data entered being regularly raised by staff.

The Committee noted that Victoria is particularly interested in the Death Audit process, having led much of its development and agreed that as the Victorian State Medical Director was participating by phone, the A/g CEO would make arrangements for a further separate discussion on the Death Audit within the next week.

- **Change management**

The Committee agreed the A/g CEO's recommendation that she would work with the South Australian State Medical Director over the next couple of weeks and bring a jointly prepared paper to the July meeting of the Committee, addressing key issues relevant to managing change within the DonateLife Network, to ensure that all jurisdictions are operating as an effective and integrated part of the national reform process.

- **Reporting and Business Plans**

The Committee agreed that the national DonateLife Network needs business plans which are jurisdictional specific but consistent nationally and reflective of the primary objective of the Network which is increasing organ and tissue donation rates. The Committee agreed that the Authority would develop and provide a business planning template which would be distributed to members next week. The Committee supported

the timelines for completion of the template and returning it to the Authority by end July 2010.

The Committee considered and endorsed the template prepared by the Authority for jurisdictional input into the Authority's Annual Report with the addition of a risk identification, assessment and management component as suggested by the Queensland State Medical Director.

The Committee agreed to the process of notifying the CEO of issues within their jurisdiction that would require the attention of senior government representatives within their jurisdiction and of the Department of Health and Ageing.

The Committee noted that the Authority, DonateLife Network and jurisdictional representatives will need to provide information as required from time to time in accordance with ad hoc requests from the Office of the Prime Minister, the Parliamentary Secretary, the Department of the Prime Minister and Cabinet and the Department of Health and Ageing.

Measure 2: Specialist hospital staff and systems dedicated to organ donation

The intent of Measure 2 is to increase organ and tissue donation rates in Australia by providing funding for selected public and private hospitals to employ trained, medical specialists dedicated to organ donation. Since 1 January 2009 the Authority has made available this funding to each State and Territory Government, with the effect that 160 doctors and nurses in 76 key hospitals throughout Australia now work as specialist organ and tissue donation clinicians, leading improved clinical staff education and awareness to increase organ and tissue donation rates in hospitals. The State Medical Directors and their DonateLife staff in each jurisdiction work closely with these hospital based staff to implement the hospital based reforms, monitoring and guiding the performance of each hospital.

Having established the national network of doctors and nurses, a key component of work in 2010-11 which will be led by the Authority and overseen by the State Medical Directors will be to expand the work of the DonateLife staff and the hospital based staff to encompass outreach services to public and private hospitals beyond the 76 key participating hospitals. The Committee agreed that each jurisdiction would articulate its strategy for achieving this outreach in the 2010-11 business plans and that private hospitals would be a particular focus of discussion at the Committee's July 2010 meeting.

Also under Measure 2, the Authority and State Medical Directors have adopted and implemented the Clinical Triggers protocol across participating hospitals. This process which is overseen by State Medical Directors will be completed in all jurisdictions during July 2010 and expanded to non-participating hospitals where that has not already occurred. The Clinical Triggers protocol is a tool adopted from New Brunswick, Canada to assist hospital staff in identifying potential donors using checklists and strict criteria.

Other key activities under Measure 2 in 2010-11 will include engagement of CEOs of all participating hospitals by the State Medical Directors, noting that this is well underway in many States and Territories. Active engagement of CEOs is a critical success factor in achieving the necessary reform within the hospital system and this work will, therefore, be reflected in each jurisdiction's business plan.

The Committee also noted that 2010-12 State and Territory funding agreements need to be executed by the Authority and each jurisdiction prior to the end of this financial year. SMDs were also asked to provide any comments on the performance information (deliverables) which has been included in the agreements by 12 July 2010.

The Committee agreed that the 2011 Annual DonateLife Forum will be held in Sydney in March 2011. The purpose of the Forum is as an information sharing and networking opportunity for all DonateLife staff, including hospital based staff. The Committee agreed that the Authority will propose an action plan to progress development of the Forum agenda, involving the education officers in each jurisdiction. The Committee will oversee the implementation of the Forum.

Measure 3: New funding for hospitals

The intent of Measure 3 is to increase organ and tissue donation rates in Australia by providing new funding to public and private hospitals to address the additional staffing, bed and other infrastructure costs associated with organ and tissue donation. The Authority has been providing States and Territories with this additional funding, based on the activities within hospitals, since July 2009.

At the first meeting of the Committee, State Medical Directors agreed that the funding under the Authority's Activity Based Funding agreement should be linked to the data collected through the Death Audit preferably from the beginning of 2010-11 and that until that time the current formula would be applied.

On 24 June 2010, the Committee agreed to review the process used in NSW for the identification of potential donors within the hospital system and that this process could be explored for national use, with the objective being a definition which will enable subsequent auditing to verify payment claims and a nationally consistent approach.

In the review of the NSW process, each jurisdiction will provide the Authority with feedback on useability and areas for adjustment during the course of the forthcoming discussion between the Authority and jurisdictions on the Death Audit.

Other matters that can be canvassed during the forthcoming discussion, or at the July 2010 meeting of the Committee include adopting an additional definition ("intended donor"), modifying the current data collection tool to verify the 'intended donor' claims, exploring the introduction of a set contribution to cover additional items to address the problem of activities not covered in the current model and possibly changing the name of the Measure

from “Activity Based Funding” to “Additional Funding for Organ Donation Activities” to better reflect the purpose of Measure 3 of the reform package.

Measure 4: National professional education and awareness

The intent of Measure 4 is to increase organ and tissue donation rates in Australia through an ongoing, nationally consistent and targeted program of recognised professional development and training, coordinated by the Authority.

The Committee considers that the key priorities for professional development and training are the hospital based staff and DonateLife staff. Inclusion of nationally consistent material in schools curricula for Year 11 and 12 students is also a priority.

On 20 May 2010, the Committee agreed on priority education activities for 2010-11. These include DonateLife Network Orientation and Induction, Targeted Training and Support, the ADAPT Program, Training Skills Workshops and Family Consent Discussion Workshops.

DonateLife Network Orientation

The Committee agreed a round of re-engagement between the Authority and State and Territories will commence in July 2010 with an aim to re-establish a shared understanding of roles and responsibilities, to ensure the performance framework is understood and in place, to inform participants about the education program and, importantly, provide an opportunity for the Network to feedback achievements, challenges and grass roots experiences.

In order for this activity to be meaningful the Committee agreed it is important for members to actively engage in the process and provide feedback and advice on issues and concerns that jurisdictions require to be addressed at orientation sessions.

The Committee further agreed that following the appointment of a permanent CEO to the Authority later in 2010, the CEO should actively engage with the State and Territory DonateLife staff, noting that the A/g CEO’s recent meetings with Queensland DonateLife staff and hospital staff, as well as the visits by the National Medical Director to most jurisdictions had been very useful in building confidence in the national system and the leadership role of the Authority.

DonateLife Network Induction

The Committee agreed that the DonateLife Induction Program should be held annually to coincide with the Annual DonateLife Network Forum. The Committee agreed that, therefore, the next induction program will be held in Sydney in March 2011. Staff employed in the DonateLife network including the hospital network between each annual induction program will receive local induction via a nationally consistent package developed by the Authority with input from all jurisdictions.

National Education Resources

The Committee agreed that a suite of 12 PowerPoint presentations (PPP) has been under development for some time, with considerable input from jurisdictions. The Committee noted that these important resources will be available for national distribution and use by the DonateLife Network by August 2010 and fall into 4 broad categories:

- Set 1 (4 PPP): Brain Death Testing, Donor Management, Donation after Cardiac Death and Pathways to Donation. These presentations are currently under review by the Death and Organ Donation Committee of ANZICS.
- Set 2 (3 PPP): Community Education for Organ and Tissue Donation; Organ and Tissue Donation for the Emergency Department and Organ and Tissue Donation for Hospital staff.
- Set 3 (3 PPP): Eye Donation, Tissue Donation and a Combined Eye and Tissue presentation.
- Set 4 (2 PPP): Generic History of Organ Donation and the Authority and Data Statistics.

The Committee acknowledged the leadership and work of the South Australian State Medical Director in the preparation of the resources and agreed to provide any final comments to South Australia on Sets 2 and 4, noting that the Authority would work with South Australia to finalise and distribute the resources for national implementation no later than August 2010.

Further discussion of Training Skills Workshops, Family Consent Workshops and ADAPT (which the Authority continues to make available to all jurisdictions) will be scheduled for the July meeting of the Committee.

The Committee also agreed that schools education will be included on the July agenda, with the Queensland State Medical Director to take a lead on this issue, given the advanced work on schools curricula in Queensland.

Measure 5: Coordinated, ongoing community awareness and education

The intent of Measure 5 is to increase organ and tissue donation rates in Australia through an ongoing, coordinated and evidence based national community awareness and education program which will increase knowledge about organ and tissue donation and transplantation and build public confidence in Australia's new donation system. The program includes phased advertising campaign activity together with other community awareness and education initiatives.

The key aim of the National Community Awareness and Education Program is to increase Australia's low family consent rate from 58% to 75% by 30 June 2012.

In the context of the importance of national effort across DonateLife Agencies to support the current national campaign, the Committee agreed to ensure that each DonateLife agency provides contributions – images and copy - on campaign activities by 28 June 2010 for inclusion in the third and final campaign e-newsletter which will be distributed on 30 June 2010 to capture and acknowledge the strong contributions of each jurisdiction.

The A/g CEO also reiterated the importance for each jurisdiction to identify how they will continue to support the national DonateLife campaign in 2010-11 and 2011-12. This could include by:

- Identifying budget support for the national campaign, noting that all Directors General had agreed to the need for a nationally consistent approach, including in relation to advertising campaign and other public material. Campaigns that are developed in parallel could contribute to public confusion and inconsistent communications activities. The A/g CEO offered to circulate the relevant record of those discussions;
- Identifying other mechanisms for ensuring longevity of the campaign (for example the NSW DonateLife agency had secured free broadcast of the campaign TVC at an NRL game) through community awareness opportunities the jurisdictions would identify and pursue in conjunction with the Authority;
- Ensuring that local strategies are consistent and aligned with the evidence-based national approach and developed in close consultation with the Authority; and
- Ensuring that all DonateLife agencies and staff within the DonateLife Network actively participate in and promote the DonateLife key messages within their communities and regions.

The Committee agreed that DonateLife Agencies will report on activities conducted during the campaign period for inclusion in the national report by 16 July 2010 in accordance with the template which will be provided by 30 June 2010.

The Committee noted that the Authority had worked hard to establish its role in providing national leadership on community awareness activities and agreed that State Medical Directors would provide strong leadership within their jurisdictions to support the national strategy and ensure that communications officers and all DonateLife staff embrace a nationally consistent and integrated work plan.

To this end, the Committee agreed that DonateLife communications staff will attend a planning workshop led by the Authority in late July-August 2010 to establish clarity around communications activities and priorities, to develop a two year plan for more cohesive and effective national programming of activities, and agree that each participant will review the national campaign evaluation report prior to attendance and actively contribute to the workshop agenda and sessions. The key outcome of the planning workshop will be the review and update of the 2010 National Communications Strategy and baseline for a national communications plan, from which DonateLife agencies will develop in consultation with the Authority individual state/territory communications plans aligned with the national strategy aims, objectives and priorities.

As part of this process of further developing a nationally coordinated effort across DonateLife Agencies, the Committee noted the draft calendar of activities prepared by the Authority and agreed that each DonateLife agency will provide details of all planned activities by 31 July 2010 to enable a comprehensive national calendar of activities to be completed by 31 August 2010.

The Committee agreed to reinforce within all jurisdictions that the primary key message within DonateLife agencies is the Discover, Decide, Discuss message (“Discover the facts about organ and tissue donation, Decide about becoming an organ and tissue donor, Discuss your decision with the people close to you”). The Committee agreed that registration is part of a secondary message of “Decide”, and promoting registration is a secondary focus of DonateLife communications. The Committee noted that the A/g CEO was progressing discussions with Medicare Australia to create stronger links between the Discover, Decide, Discuss messaging and material including and related to the Register produced and maintained by Medicare Australia.

The Committee also agreed that each DonateLife agency will contribute copy and images on a monthly basis (by the 21ST of each month) to the national DonateLife e-newsletter, noting that each DonateLife agency will have a dedicated space in the e-newsletter, to promote a continued national approach and acknowledging the strong contribution of all jurisdictions.

The Committee noted that the Authority will hold a stakeholder gathering in September 2010 to which all National Communications Charter signatories will be invited to participate and that the agenda will include progress under Measure 5, as well as to provide a forum for briefing and planning on the next national campaign activity and sector-wide planning, including Australian Organ Donor Awareness Week. The Committee discussed the concept of rebranding the name of the week to DonateLife Week reflecting the new national approach of the sector, the current exclusion of eye and tissue, and the positioning of DonateLife as the national cause of organ and tissue donation. It was noted that renaming will provide a strong marketing platform to elevate media and public attention given to the week, which will be supported by a national DonateLife advertising campaign. The Committee was supportive of the concept, if there was a process to transition the name change and for broader stakeholder engagement. The Committee agreed to consider the proposal further, with additional discussion about an appropriate approach to occur at the July 2010 meeting.

The Committee agreed to submit the names of all nominated spokespeople from their respective jurisdictions to the Authority and that all authorised spokespeople to undergo media training approved by the Authority if required. The committee was also informed that media training had been provided to new DonateLife staff in some jurisdictions.

The Committee noted that the Authority is required to keep a register of all public uses of the DonateLife brand and that the Authority would write to all jurisdictions seeking samples (electronic or hard copy) of all such material. The Authority committed to

carefully define the parameters of those materials to be submitted, noting that jurisdictions will in some cases need to consult with staff and hospitals to fulfil this reporting obligation.

The Committee noted that in-house design support is available from the Authority to assist agency and Network staff and that Authority staff are available to advise on, assist with and proof material before it is printed.

The Committee also:

- Agreed that the Authority should develop, in conjunction with all jurisdictions, an engagement strategy targeting GPs and that all DonateLife agencies will provide information to feed into the upcoming communications planning workshop on capacity and expertise relating to GP engagement.
- Noted the need for a national communication strategy to effectively engage with special audiences and agree that each jurisdiction will engage in supporting the development of this important strategy by identifying relevant expertise within the DonateLife network as well as established best practice in similar communication.
- Noted that DonateLife agencies are encouraged to promote the community awareness grants within their respective jurisdictions and to identify potential opportunities for partnership of activities which directly support the National Community Awareness and Education Program aims and objectives.
- Noted the important work being undertaken by the Reputation Group and agree that DonateLife agencies will work proactively to support the work of the Reputation Group including requests for profiles, contacts and other media relations activity.
- Agreed that each DonateLife agency will continue to develop and provide story and images for a national bank of talent for use in a range of communications activities, including media, the DonateLife website and publications.
- Agreed that the Authority and DonateLife agencies will provide a minimum 24 hours notice of planned media releases or press conferences to enable all relevant staff to be notified and prepared in advance and that in the rare circumstance this is not possible, it will be the subject of discussion between the Authority's CEO and the relevant SMD(s).
- Agreed that the Authority and DonateLife agency will mutually inform each other of requested interviews for national media outlets to enable all relevant staff to be notified and prepared in advance and to ensure the most appropriate spokesperson is presented.
- Noted the existing performance indicators in relation to Measure 5 as set out in Attachment B and that further work will be undertaken in conjunction with jurisdictions to refine the performance indicators on the basis of the benchmark research currently underway.
- Agreed that each DonateLife agency will identify existing relationships that could be developed to become DonateLife Families or Ambassadors by 31 July 2010.

Measure 6: Donor Family Support Service

The intent of Measure 6 is that through a nationally coordinated approach deceased donor families will be provided with respectful support which is responsive to the needs of each family.

The key elements of Measure 6 are:

- Donor Family Support coordinators in each State and Territory.

The Committee noted that the Authority has made funding available for these positions since April 2010 and agreed the importance of filling each of the positions as soon as possible and no later than end July 2010.

The Committee agreed that the positions would be filled in the interim pending permanent filling within this timeframe. This position will fulfil an important part of the national reform package, complementing and enhancing the support provided by other staff of the DonateLife Network including the State Medical Directors and the Organ Donor Coordinators.

The importance of the role warrants these positions being filled as a priority to support State Medical Directors and Organ Donor Coordinators to continue their responsibilities.

Jurisdictions are to advise the A/g CEO of the arrangements in hand to fill these positions as soon as possible and no later than the end of July.

- Tools to support donor families in hospital settings. The Committee endorsed the Donor Family Support Service Framework and the resources developed for the national DonateLife Network including:
 - In Reflection Booklet
 - National Donor Family Charter
 - Donor Family Support Discussion Checklist
 - Donor Family Support Contact Record Form
 - Transplant Recipient Correspondence Guidelines
 - Donor Families Correspondence Guidelines
- Western Australia commented on the font in relation to the In Reflection Booklet and recommended that the Authority consult with donor families on the redesigned Booklet. The Committee noted that these resources were intended for launch and implementation from July 2010, reemphasising the need for Donor Family Support Coordinators to be in place in each jurisdiction. The Committee also sought advice as to how the resources were to be implemented. The Authority undertook to consider this further and will lead a small working group to develop an implementation plan for the resources. The Authority, in conjunction with the Committee, will write a paper for the Australian Health Ministers Advisory Council (AHMAC) informing them of the Framework, Resources and implementation plan. The Committee noted its ongoing role to oversee the implementation of these resources.
- Thanksgiving Services. The Committee agreed that while each Thanksgiving Service should be tailored to the needs and wishes of the donor families and recipient families in each jurisdiction, the services need to reflect that they are part of the DonateLife suite of services and the Committee endorsed the order of service template that will help to achieve this. State Medical Directors agreed their leadership role in supporting Donor Family Support Coordinators within the

DonateLife Agencies to integrate these services within their broader work plans and responsibilities (Measure 5 refers).

The Committee endorsed the current Implementation Plan for this Measure, including the proposal to send a noting paper to the AHMAC on the Donor Family Support Service.

Measure 7: Safe, equitable and transparent national transplantation process

Under this measure, the Authority, in collaboration with the relevant professional societies, is responsible for maintaining and auditing the implementation of approved national transplantation protocols and standards. This will ensure that the management of transplant waiting lists and the allocation of organs and tissues is effective, equitable and transparent, regardless of where the donor and recipient reside.

Prior to the Authority's establishment, the Transplant Society of Australia and New Zealand was engaged to develop nationally consistent, safe, equitable and transparent process for the management of transplantation waiting lists and the allocation of donated organs across Australia.

TSANZ has now completed the work required of it and provided a protocol to the Authority. The National Medical Director noted that TSANZ had identified some ethical and technical issues (such as the need or otherwise for an appeals mechanism, the need or otherwise for an alternate list) that were beyond the scope of their work. The SMDs supported the A/g CEO's advice that issues that could not be resolved by TSANZ would be referred to the Transplantation Expert Advisory Committee.

The Committee noted that the Authority would circulate a copy of the protocol to members to discuss the practice implications with their Organ Donor co-ordinators and to provide feedback by 28 July 2010. The Authority would also prepare a draft paper to the Australian Health Ministers' Advisory Council regarding the document which would be circulated to members for comment. The Authority will also write to key professional groups about the protocol.

Until the new protocol is endorsed by relevant groups the existing protocols will continue to apply.

The Committee also noted that the Authority would provide members with a proposal at the July meeting for further review of the protocol in consultation with both clinical and non-clinical (including non-government organisations) input.

Measure 8 – National Eye and Tissue Donation and Transplantation Network

The intent of Measure 8 is to increase organ and tissue donation rates in Australia by introducing systems that will deliver a coordinated, accountable, national tissue transplantation service for patients across Australia.

The Committee noted that a set of three PowerPoint Presentations in relation to eye and tissue have been developed under Measure 4 and will be available from August 2010:

- ***Information for Hospital Staff - Understanding Eye and Tissue Donation.***
The PowerPoint presentation has been developed primarily for hospital staff and covers both eye and tissue donation. It also includes a number of slides which are generic in nature. While there are some 54 slides in all, there are options for the presenter to be selective and to tailor the presentation to the audience at hand. The presentation is intended to give a general overview of eye donation and tissue donation in Australia, and specifically how it relates to donor identification, referral and coordination.
- ***Information for Hospital Staff - Understanding Eye Donation***
The presentation (some 33 slides) is intended to give a general overview of eye donation in Australia. However, the eye banking process and preservation procedures are not covered in any detail, as these processes are somewhat removed from what hospital staff need to know about *donation*. This specific information will be available from local Eye Banks if required.
- ***Information for Hospital Staff - Understanding Tissue Donation***
This presentation has some 40 slides. As per the Eye Donation presentation, described above, the tissue banking process and preservation procedures are not covered in any detail, as these processes are somewhat removed from what hospital staff need to know about *donation*. This specific information will be available from local Tissue Banks if required.

The Committee agreed that the Authority should progress the relevant recommendations of the HOI report by working with the Queensland State Medical Director and the Department of Health and Ageing to prepare a paper and supporting business case for an efficient system of retrieval, processing and storage of tissue in Australia considering the available existing facilities and the opportunities, risks and benefits of rationalising these to achieve enhanced outcomes.

This paper will be available for discussion at the July meeting of the Committee with a view to briefing the Australian Health Ministers' Advisory Council and other relevant senior decision-making groups in order to progress Measure 8.

Measure 9 - Additional national initiatives, including living donation programs

The intent of Measure 9 is increase organ and tissue donation rates in Australia by establishing national protocols to guide initiatives including the practice of 'paired kidney exchange' between living donors and recipients, and living donor liver transplantation.

The Australian Paired Kidney Exchange program (or AKX Program) aims to maximise the number of live donor kidney transplants that can be performed in Australia by identifying biologically compatible donor/recipient pairs.

Another initiative progressed under this measure is the Donation After Cardiac Death protocol (DCD protocol), the development of which was a recommendation of the Australian Health Ministers' Advisory Council (AHMAC).

Australian Paired Kidney Exchange (AKX) Program

The Committee noted that the Authority and National Coordination Centre in Western Australia were progressing a number of key issues required to implement the AKX Program including entering into an agreement for national transportation arrangements for paired kidneys with the National Coordination Centre.

The Committee heard an overview of progress and next steps from Professor Paolo Ferrari and acknowledged the strong leadership he has shown in progressing the development of this program. The Committee thanked Professor Ferrari for his work.

The Committee also thanked the Authority for its work including in developing with Dr Ferrari the storage containers for transport of paired kidneys and noted the interest from transplant units nationally to see if these storage and transport equipments could be utilised for solid organs more broadly. The A/g CEO offered to facilitate a discussion nationally on this broader adoption noting that costs of producing the revised equipment to the AKX standard would be a cost to States and Territories (as is the cost of the current equipment). The Committee agreed this approach.

The Committee also noted that formal endorsement of the *AKX User Manual* has been sought and now received by all members of the Authority's Principal Committee, with the exception of Victoria who had noted it.

The Committee agreed that the next steps include the Authority preparing relevant briefing for out of session consideration by Australian Health Ministers' Advisory Council.

The Committee noted that at the Tissue Typing and NOMS Workshop held on 28 April 2010, tissue typing laboratories raised concern about funding structures for AKX tissue typing activities. The Authority has written to Chief Medical Officers in May 2010 requesting them to communicate funding structures with their state tissue typing laboratories.

The Committee noted that the Authority is developing an AKX Consultation and Evaluation Strategy to review the first six months of the AKX Program. A copy of this Strategy will be sent to State Medical Directors for consideration at the July meeting.

The Committee agreed that it would have a continuing role to oversee the implementation and review of the AKX program.

Donation after Cardiac Death Protocol (DCD)

The Committee noted that the DCD Protocol was endorsed by the National Medical Health and Research Council (NHMRC) on 5 March 2010 however, following endorsement,

changes were requested to the legal sections of the protocol and a clinician raised concern about the wording on post-mortem interventions.

Advice on post-mortem interventions was sought from the Transplant Society Australia New Zealand and provided to the CEO of the NHMRC. The proposed changes to the Protocol were provided to NHMRC Council Members for comment and endorsement. The Authority is awaiting advice about final endorsement.

The Committee agreed that following NHMRC endorsement of the DCD Protocol and handover to the Authority that within three months the Authority will prepare relevant briefing to the Australian Health Ministers' Advisory Council as well as seeking the endorsement of professional associations and colleges. The Committee further agreed that the Authority would seek input from Committee members regarding implementation of the DCD Protocol in each jurisdiction within that timeframe.

Next meeting

The Committee agreed that the next meeting will be held in Canberra on 22 July 2010.

The Committee agreed that officials be invited to attend the July meeting of the SMDs given the agenda items to be discussed and resolved at that meeting.