# NHS BLOOD AND TRANSPLANT
# ORGAN AND TISSUE DONATION AND TRANSPLANTATION DIRECTORATE

## THE TWENTY-FOURTH MEETING OF THE MULTI-VISCERAL AND COMPOSITE TISSUE ADVISORY GROUP MEETING AT 10:30 AM ON WEDNESDAY 16 MARCH 2022, VIA MICROSOFT TEAMS

**Present**

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| Andrew Butler | **Chair MCTAG /** Cambridge University Hospitals |
| Philip Allan | Oxford Intestinal Transplant Centre |
| Richard Baker | Associate Medical Director – Governance, NHSBT |
| Ian Currie | Clinical Lead for Organ Retrieval, NHSBT |
| Samantha Duncan | Recipient Co-Ordinator Rep |
| Simon Gabe | Adult Small Bowel and BAPEN Representative |
| Susan Hill | Paediatric Gastroenterologist and BSPGHAN Rep |
| Jonathan Hind | King's College Hospital |
| Simon Kay | Composite Tissue Rep |
| Lisa Mumford | Statistics and Clinical Research, NHSBT |
| Sarah Peacock | BSHI Rep |
| Srikanth Reddy | Oxford University Hospitals |
| Matthew Ridley | Postdoctoral Research Associate, About Face, University of York |
| Neil Russell | Cambridge Intestinal Transplant Centre |
| Lisa Sharkey | Cambridge Intestinal Transplant Centre |
| Hector Vilca-Melendez | King's Intestinal Transplant Centre |
| Sarah Watson | NHS England |
| Julie Whitney | Head of Service Delivery, OTDT Hub |

**In attendance**

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| Caroline Robinson | Advisory Group Support, NHSBT |

| | Item | Action |
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| **1** | **Welcome and Apologies** | |
| | A Butler welcomed all to the meeting. Apologies were received from Fay Boundalberti, Chloe Brown *(Lisa Mumford attended on her behalf),* Chris Callaghan, Girish Gupte, Monica Hackett, Rachel Hogg, Sian Lewis, Elizabeth Murphy, Tracey Rees, John Richardson, Khalid Sharif, Michael Stokes, Craig Wheelans | |
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| **2.** | **Declaration of interest in relation to the agenda** | |
| | There were no declarations of interest at the meeting. | |
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| **3.** | **Minutes and Action Points of the MCTAG meeting held on 13 October 2021** – **MCTAG(M)(21)02** | |
| 3.1 | Accuracy – The Minutes of the last meeting on 13 October 2021 were approved. | |
| 3.2 | Action Points **MCTAG(AP)(21)02** | |
| 3.2.1 | AP1, Item 2.2.1 – The Minutes for the meeting of 17 March 2021 were amended as agreed. | |
| 3.2.2 | AP2, Item 2.1.1 - Minutes of MCTAG Meeting 17 March 2021 **-** Minute 2.2: NBAS – Prolonged waiting time for paediatrics – In the absence of G Gupte, H Vilca-Melendez highlighted 2 patients who spent 1000 days on the waiting list. One was given an emergency adult small bowel transplantation due to deterioration in ITU despite being in the same tier as the hepatoblastoma patients. It is | **Ongoing** |

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| | felt it is unacceptable to leave patients on the waiting list for such a long time and while numbers are small, these recipients need to be highlighted within the transplant community. There has been agreement previously that these patients would be put into the same tier as hepatoblastoma patients to improve their chances of transplantation and while a lot of offers are inappropriate as a result, monitoring is needed to assess whether this helps to reduce the waiting list. It is agreed that split livers while they may help are not a solution for multi-visceral/small patients and there will be a further discussion as they could be used for hepatoblastoma patients. | |
| 3.2.3 | AP3, Item 2.2 - Prolonged waiting time for paediatrics - J Whitney has sent the Comms link to J Hind to raise the visibility of paediatric bowel donation through public campaigns. | |
| 3.2.4 | AP4, Item 2.2 - Patient survival after intestinal transplantation | *See Item 6.1 below* |
| 3.2.5 | AP5, Item 2.2 - M&F Proposal: Intestinal failure transplantation – S Watson stated that she and S Gabe had discussed this proposal with NHSE Comms to improve awareness of bowel transplantation through a publicity campaign who are keen to take the issue forward. Further progress has stalled, and a conversation is now needed with D Manas to re-think the comms strategy and to define priorities. | *See also Item 13.1 below* |
| 3.2.6 | AP6, Item 5.1 – Addition of graft survival rates to the annual report – This is not yet available but will be included in the annual report | *See Item 6.1 below* |
| 3.2.7 | AP7, Item 6.1 - Performance report of the National Bowel Allocation Scheme (NBAS) | *See Item 7.1 below* |
| 3.2.8 | AP8, Item 8 - Potential bowel donors and location – This item is deferred to the next meeting as there is no update and will be included in the annual report. Data checking is needed before further discussion. | **C Brown** |
| 3.2.9 | AP9, Item 8 - Potential bowel donors and location - It was previously agreed that it would be beneficial to have the weights of donors offered from overseas in the next report, as rejection rates will help inform decisions re: transplantation of small recipients | **C Brown** |
| 3.2.10 | AP10, Item 9 - Conflict in using smaller donor organs in MV recipients and for paediatric hepatoblastoma patients<br>Clarity is needed around the definition of 'small' donor organs. The suggestion is if the weight of paediatric patients is listed at a minimum of 20kg, and maximum of 30 kg, this would possibly restrict the number of offers in that category.<br>**ACTION: A Butler, H Vilca-Melendez (Kings), K Sharif (Birmingham) and a surgeon from Leeds will have a virtual meeting to look at this issue and options for small adults** | **A Butler, H Vilca-Melendez, K Sharif, + Surgeon from Leeds** |
| 3.2.11 | AP11, Item 10 - Transfer of UK intestinal data to the International Transplant Registry (ITR) - | *See Item 10 below* |
| 3.2.12 | AP12, Item 11.1 - Quality of Life Working Group: data collection – Adults | *See Item 11.1.1 below* |
| 3.2.13 | AP13, Item 11.1.2 - Quality of Life Working Group: data collection - Paediatrics | *See Item 11.1.2 below* |
| 3.2.14 | AP14, Item 14 - Impact of IF commissioning on Intestinal Transplant services – S Gabe will raise this issue at the first meeting of the IF centres in Salford. The proposal is to ask for interest from integrated centres and home PN centres to ensure representation from all tiers of PN provision, with reference centres providing a degree of oversight. It is hoped this will enable better communication with the IF network and new insights. | |

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| 3.2.15 | AP15, Item 17 - Addition of chimerism testing to service specification | *See Item 17 below* |
| 3.2.16 | AP16, Item 19.1 - Update on face transplantation – A meeting arranged by About Face was attended by M Ridley but no proposal for a way forward was agreed. Despite initial optimism due to progress with hand transplantation, obstacles facing face transplantation are too great for centres to take forward currently. | **CLOSED** |
| 3.2.17 | AP17, Item 19.3 - Review of CMV and EBV infections in Intestinal transplantation UK wide experience – incidence, outcome and strategies – A Butler has contacted A Clarkson regarding inconsistent reporting of EBV status across the UK due to some centres offering this service and some not. While EBV status is not a critical issue for some organs, there is a substantial risk for MV recipients if EBV is not reported and this can determine whether organs are utilized. A national programme to unify donor characterization starts in April and this issue can be addressed in the national service specification to ensure all microbiology labs report EBV status.<br>**ACTION: R Baker to take the issue to donor characterization meetings.** | **A Butler to meet A Clarkson**<br><br>**R Baker to discuss at donor charact. meeting.** |
| 3.2.18 | AP18, Item 19.4 - Use of CMV positive donors in CMV negative patients – This item is deferred until there is a response from G Gupte | **G Gupte to report on progress** |
| 3.3 | Matters Arising, not separately identified – NAD | |
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| **4.** | **Medical Director's Report** | |
| 4.1 | Organ Donation and Transplantation management during COVID-19 pandemic - In D Manas's absence, R Baker highlighted the following issues:<br>• Weekly donors are currently 30 with 60-70 transplants resulting. Pre-pandemic results showed 85 transplants per week. At year end results are likely to be 1400 donors in total whereas pre-pandemic this figure was c.1600, but overall, this figure is better than last year's result of 780 donors. It is important to note that COVID numbers are increasing and will be harder to track once tests disappear.<br>• COVID-19 positive donors are likely to increase. Guidelines written with BTS indicate various levels of risk for transplantation. Many more donors in future are likely to have had COVID and some anxiety was expressed due to the mucosal burden connected to bowel transplantation. Early data at the start of the pandemic showed ongoing faecal shedding that could be quite prolonged. Infection could also compromise the graft leading to the need to re-transplant a recipient and the view was expressed that transplantation would only take place if a patient was unlikely to live without a transplant. Differences between positive active infection and past infection also have varying risks and little is understood currently around re-activation of infection. The burden of immunosuppression needed by patients is also an important issue. It was agreed that the policy adopted by the lung centres would be followed.<br>**ACTION: R Baker to find out what lung centres are doing.**<br>• The Assessment and Repair Centres for Organs (ARCS) – The advantage of these centres is the potential to utilise | **R Baker** |

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| | marginal organs that have been reconditioned, equity of access, daytime surgery and sustainability. However, plans to develop these centres (with lungs leading and liver following) are on hold as there is no funding agreed currently. It was agreed that ARCS are unlikely to be developed for MV transplants due to inherent complications at present.<br>• Organ Utilisation Group is likely to report in May. | |
| 4.2 | Governance – One incident was reported. The weight for a young donor was incorrectly listed and as a result the organ was not offered. On review, it was felt that the proposed recipient was not disadvantaged due to be being particularly sensitized. The graft was not appropriate for that reason rather than an incorrect weight being recorded and so no further action was taken. The meeting discussed whether accurate weights should be given as these are frequently estimated and can lead to a mismatch in size of organ for donor recipients. It is acknowledged however, that this is hard to achieve when someone is critically ill or brain stem dead. The time spent in ITU can also affect the weight during treatment. It was agreed that this would be discussed in a subgroup.<br>**ACTION: J Whitney to take back issue of accurate weights to Operations Team.** | **J Whitney** |
| 4.2.1 | Non-compliance with allocation - NAD | |
| 4.2.2 | Detailed analysis of incidents for review - NAD | |
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| **5.** | **OTDT Hub Update – MCTAG(22)15** | |
| | • The review of the HTA B Form was circulated and figures show good return rates for small bowel.<br>• An IT release on allocation scheme came out in February but an IT glitch has been found in testing which impacts on coding. Centres are asked to contact the Hub if registering Group 2 patients until this IT problem is resolved. | |
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| **6.** | **Summary from Statistics and Clinical Research – MCTAG(22)01** | |
| 6.1 | L Mumford introduced herself as Head of Organ and Tissue Donation and Transplantation Studies and attended the meeting for C Brown. The circulated paper lists the statistician leads working on each organ area. Work continues to implement development of more extensive intestinal data. | |
| 6.2 | Patient survival after intestinal transplantation – **MCTAG(22)02 –** This paper was circulated prior to the meeting and the following issues were discussed:<br>• Conditional survival – paediatric teams welcomed results shown in the data set and are pleased with figures for 10-year survival which mirrors international data for liver. It was queried whether liver affects the data as liver/bowel procedures often are due to early sickness or are done late and end up being life-saving surgery.<br>• It was agreed that it would be useful to define measures for graft failure and that stoma output is possibly too difficult to monitor. Suggested measures could be eg:<br>o Need for PN in 28 days – Yes/No<br>o Expected irreversibility at 3 months<br>o Explant<br>o Relisting for transplant. | **P Allan, L Sharkey, J Hinds, G Gupte** |

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| | **ACTION: P Allan to arrange 2-hour virtual meeting to discuss with L Sharkey, J Hinds and G Gupte** | |
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| **7.** | **National Bowel Allocation** | |
| 7.1 | Performance report of the National Bowel Allocation Scheme – **MCTAG(22)03 –** This paper was circulated and discussed at the meeting. Those present were reminded that centres can update and return to NHSBT sequential liver intestinal forms as factors change for patients. | |
| 7.2 | Disproportionate waiting time for liver and bowel patients compared to a liver patient only – **MCTAG(22)04 –** This paper was circulated prior to the meeting. The median waiting time for isolated livers is 72 days (adults) and 74 days (paediatrics). Isolated livers have issues of age and co-morbidities to consider and so there is a smaller subset of potential donors along with additional constraints of sensitization and size. | |
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| **8.** | **Group 2 Bowel Transplants** | |
| | *See Item 5 above.* | |
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| **9.** | **Update from meeting re: Hand Transplantation** | |
| | S Kay reported increasing numbers of applicants for hand transplantation. A dozen procedures have now been completed successfully. There is a responsibility for surgeons to inspect the hand prior to acceptance and so donors have had to be close by geographically. Many hand recipients have also had multi-organ sepsis, and this has created a need for a bigger donor pool. As a result, some patients are waiting 3-4 years for a transplant and so more donors are needed. Most donors currently come from the northwest and the plan is to manage the waiting list by extending the donor pool from outside the immediate area and to work with units in the northeast and Midlands (and possibly the south). Including hand transplantation on the donor form would be helpful and is likely to increase consent as donor families are unlikely to override consent for this. There are also plans to develop training videos for SNODs. | |
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| **10.** | **Transfer of UK intestinal data to the international transplant registry (ITR)** | |
| 10.1 | UK Joint intestinal rehabilitation meeting – J Hind reported that after some problems, the International Transplant Registry (ITR) is now hosted by TTS, is properly funded and is a REDCAP database. This is governed by the Council and Registry committee and the Scientific Committee and there is a data manager in post. A meeting is planned in the next few months with Rob Fenwick from the Scientific Committee, C Brown, (NHSBT) and Eric Pal (Data Manager). Agreement is needed about what data will be included so this can be sent to NHSBT and sent into the Registry once. A Butler emphasized the need for consistency regarding graft definitions for centre returns and international designation and the following designations were suggested:<br>• A full MV transplant consists of stomach, liver pancreas small bowel +/- colon.<br>• A modified MV transplant excludes the liver<br>• A small bowel transplant is small bowel +/- colon and +/- pancreas | **J Hind** |

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| | There was discussion whether the pancreas should be considered as an intestinal organ, but it was emphasized that consistency with international designations is important.<br>**ACTION: J Hind to organize meeting to discuss what data to include** | |
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| **11.** | **Update from Working Groups** | |
| 11.1 | Quality of Life Working Group: data collection – P Allan reported as follows: | |
| 11.1.1 | Adults – P Allan stated that there is now a need to move forward to making decisions on what data to collect. The EQ-5D and SSZ6 questionnaires are being used as generic data tools and HPN-QOL and ITx QoL for disease specific data and there is now a need to reduce the numbers of questions included to 8 easily answerable questions. It is felt that getting someone to do a proper research project on this would help with progress. It was noted that Lorna Marson (new AMD for Research at NHSBT) will be contacting all advisory group chairs to discuss quality of life for recipient outcomes as this is a key part of future strategy. | |
| 11.1.2 | Paediatrics – In the absence of C Bambridge, P Allan reported that this needs to be a national project. There is no progress to report. | |
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| **12.** | **Appeals/Priority – update** | |
| | Two appeals/priority cases were highlighted by A Butler:<br>• There was a delay in registering a liver/bowel patient on 11 October so additional points were allocated to the individual.<br>• An 11-months old patient weighing 7.5 kilos with end stage bivalves and ongoing bleeding from stoma, varices and megacystis-colon was initially listed as liver/bowel on 26 November. The liver disease progressed, and the patient was moved to the hepatoblastoma list and removed from the intestinal list with transplantation taking place on 7 December. This reflects policy to register small patients I the hepatoblastoma tier. | |
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| **13.** | **M&F Proposal: Intestinal Failure Transplantation** | |
| 13.1 | M&F Proposal – Potential funding for film (*see Item 3.3.5 above*) – S Gabe has not been able to take this any further. The plan now is to reinstate the media plan including both adult and paediatric issues. It was agreed that hand transplantation issues will also be included in this plan going forward.<br>**ACTION: S Gabe to work on this with S Watson and S Kay** | **S Gabe/S Watson/S Kay** |
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| **14.** | **Impact of IF Commissioning on Intestinal Transplant Services** | |
| | Lisa Sharkey stated that this item was included originally due to feelings of inequity regarding the way in which IF designation is allocated and to ensure representation from 2-3 IF centres. A mechanism has now been implemented to address any inequities and it was agreed this item can be removed from future agendas. | |
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| **15.** | **National Paediatric Intestinal Rehabilitation and Trans-plant Meeting** | |
| | S Hill reported that this was initiated to implement a national paediatric interest meeting to take place 2-3 times per year. So far, two meetings have been held with the most recent taking place last | |

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| | month when two cases were presented with good discussion. A further meeting is planned in 2-3 months' time. Meetings are organised via the transplant centres and are expected to continue. | |
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| **16.** | **Update on NASIT** | |
| | L Sharkey reported that NASIT continues to have monthly meetings. In June, the 100th meeting will be held, and it is hoped this will be a face-to-face event to allow as many members to attend as possible with an evening celebration to mark NASIT's achievements. | |
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| **17.** | **Establishment of a centralised facility for chimerism testing** | |
| | The need for a centralised facility for chimerism testing to serve all centres was discussed. Currently the turnaround for testing is around 3 weeks as it is linked with graft monitoring for bone marrow transplant rather than investigating significant pathology. While this is not an issue for most solid organ transplantation it is a problem affecting 10-20 liver transplants per year. It is proposed that one unit could receive samples to test from all transplant units to achieve faster turnaround for chimerism testing. It was agreed that having a central point for faster turnaround of testing would be welcomed and would be good for data collection as well.<br>**ACTION: S Watson to discuss commissioning of the service with S Peacock** | **S Watson/S Peacock** |
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| **18.** | **Feedback from Liver Advisory Group Meeting of 24 November 2021 (LAG(M)(21)02) – MCTAG(22)05** | |
| | The Minutes from the Liver Advisory Group meeting held on 24 November were circulated. Of relevance to MCTAG were discussions regarding the hepatoblastoma tier and a pilot project for neuroendocrine tumour metastases as an indication for liver transplant. It was agreed that there are some circumstances that have involved a need for bowel transplant at the same time to get rid of a primary or unknown primary. | |
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| **19.** | **Any Other Business** | |
| 19.1 | Multicentre collaborative studies and research – It was confirmed that CMV and GBHD are the only two collaborative research studies currently. | |
| 19.2 | Exploration of options regarding use of split liver transplants as part of an MVT – On the back of prolonged waiting times for liver containing grafts, this considers paediatric and adult bowel transplant options using a split liver. This would require using a set of organs for whom the left lateral segment has already been retrieved for hepatoblastoma and would have to be done in association with in-situ splitting with the donor. While this is not standard for splitting, this is routinely undertaken in Europe and can be done in the UK under certain circumstances. There would be complexity regarding theatre availability and surgical expertise and so this would need to be requested at the time of the request. Centres appear willing to undertake this, but it is noted that local hospitals are unlikely to have the theatre space or scrub nurses. This will be discussed further if opportunity to do the procedure arises. | |
| 19.3 | Revisiting the allocation protocol / paradigm with regards to listing priorities – **MCTAG(22)06** – This issue is raised due to increasing waiting times and the need to ensure the right organs are offered to | |

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| | the right patients. Looking at the current allocation protocol, it is agreed that the thresholds showing two tiers of bilirubin don't reflect acuity of illness and urgency and are too high. Centres need to consider the following actions to make decisions on any changes to the current protocol:<br>• Assessment of previous data and outcomes for patients<br>• Completion of sequential data forms so that bilirubin is measured at regular intervals and recorded at time of listing and at transplant.<br>• Recording bilirubin for patients who die while on the waiting list.<br>• Any jaundice and bilirubin of 200 is too late for transplant and there is a need to ensure that people do not reach this frail state prior to transplant. Figures for numbers of people who reach this stage should be recorded.<br>• As there is not a lot of intestinal data yet, consider using the international registry to compare UK data with other countries<br>A lot of work as well as IT changes are needed for any alteration to the allocation policy and so will take some time to implement. | |
| 19.4 | Formal cessation of post-transplant monitoring forms - **MCTAG(22)07, MCTAG(22)08, MCTAG(22)09, MCTAG(22)10, MCTAG(22)11 –** These forms were circulated as a guide to develop a suitable validation/verification procedure. S Peacock stated that post-transplant HLA forms are not being sent into NHSBT due to manual transcription burden. It is agreed that it is essential to understand the effect of HLA-antibodies on post-transplant outcomes, so she has met E Allen and C Brown from Statistics and Clinical Research, NHSBT to consider a better system to collect data either live, prospectively or retrospectively. Data presented at the symposium in January uses the process that has been developed and it is proposed that rather than simply storing data at OTDT at NHSBT, samples will be taken by H&I labs at stipulated timepoints as well as when clinically relevant (eg 1,3,6 and 9 months) to analyse all transplant issues as well as post-transplant survival. It is hoped that by centres taking back ownership, data will be more granular and informative. It remains essential that NHSBT continues to receive the data.<br>**ACTION: S Peacock to define what data to extract and to discuss with C Brown (NHSBT) and H&I colleagues** | **S Peacock / C Brown** |
| 19.5 | Review of MCTAG guidelines for HLA Ab screening – **MCTAG(22)12 –** It is acknowledged that the guidelines are old and it is proposed a draft of a re-write is considered. Defined MFI cut off levels has been removed.<br>**ACTION: All to send any comments on how an approval system may work going forward to A Butler.** | **ALL** |
| 19.6 | QUOD named UK Biobank of the Year - **MCTAG(22)13 –** QUOD's success winning UK Biobank of the Year was acknowledged. Although it was agreed that it would be achievable to have a biobank of healthy non-transplanted bowel tissue, it was noted that a lot of QUOD's work is not related to transplant and therefore samples taken may not be available for transplant centres' own research. | |
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| **20.** | **Date of next meeting** – ***Weds 14 September 2022***. | |
| | It is likely that this date will be re-scheduled due to a clash with another meeting. Further information will follow in due course, and it is hoped this will be a face-to-face meeting in London. | |