NHS BLOOD AND TRANSPLANT ORGAN AND TISSUE DONATION AND TRANSPLANTATION DIRECTORATE

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

Present

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Andrew Butler	Chair MCTAG / Cambridge University Hospitals
Philip Allan	Oxford Intestinal Transplant Centre
Irum Amin	Cambridge University Hospitals
Richard Baker	Associate Medical Director – Governance, NHSBT
Chloe Brown	Statistics and Clinical Research, NHSBT
Chris Callaghan	Associate Medical Director – Organ Utilisation, NHSBT
Peter Friend	Oxford Intestinal Transplant Centre
Girish Gupte	Consultant Paediatric Hepatologist, Birmingham
Susan Hill	Paediatric Gastroenterologist and BSPGHAN Rep
Jonathan Hind	King's College Hospital
Craig Jones	Lay Member, NHSBT
Simon Kay	Composite Tissue Rep, Leeds Hand Transplant UK
Derek Manas	Medical Director, OTDT, NHSBT
Sarah Peacock	BSHI Rep
Lisa Sharkey	Cambridge Intestinal Transplant Centre
Hector Vilca-Melendez	King's Intestinal Transplant Centre
Sarah Watson	NHS England
Anthony Wrigley	Lay Member, NHSBT

In attendance

Caroline Robinson	Advisory Group Support, NHSBT

	Item	Action
1	Welcome and Apologies	
	A Butler welcomed all to the meeting. Apologies were received	
	from Ayesha Ali, Carly Bambridge, Marius Berman, Fay	
	Boundalberti, Ian Currie, Simon Gabe, Monica Hackett, Craig	
	Wheelans, Julie Whitney	
2.	Declaration of interest in relation to the agenda	
	There were no declarations of interest at the meeting.	
	There were no decidrations of interest at the meeting.	
3.	Minutes and Action Points of the MCTAG meeting held on 16	
	March 2022 – MCTAG(M)(22)01	
3.1	Accuracy – The Minutes of the last meeting on 16 March 2022	
	were approved. One amendment is made to Item 19.1 - GBHD is	
	changed to GVHD – Graft Versus Host Disease.	
3.2	Action Points MCTAG(AP)(22)01	
3.2.1	AP1, Item 2.2.1 - 17/3/21) – H Vilca-Melendez highlighted 2	a) A Butler / H
	patients who spent 1000 days on the waiting list at a previous	Vilca-
	MCTAG meeting in March 2021. One was given an emergency	Melendez
	adult small bowel transplantation due to deterioration in ITU	
	despite being in the same tier as the hepatoblastoma patients. It is	b) D Manas / J
	felt unacceptable to leave patients on the waiting list for such a	Whitney
	long time. This issue has been taken to the Liver Advisory Group	
	and in particular, MV patients coming below hepablastoma in liver	

	only grafts when it would be possible to use split livers for these	
	patients. ACTION: a) A Butler to contact H Vilca-Melendez to check on	
	progress with contacting Leeds (Raj Prasad), Birmingham and	
	Kings.	
	b) D Manas to find out if J Whitney is able to help with this	
	issue (eg a manual process to highlight a small donor who	
	would benefit from a split donor)	
3.2.2	AP8, Item 3.2.8 - (16.3.22) Potential bowel donors and location -	See Item 10
	This is deferred to the next meeting as there was no update and	
	data needed validation before inclusion in the annual report.	
3.2.3	AP9, Item 3.2.9 – (16.3.22) Potential bowel donors and location – It	See Item 10
	was previously agreed it would be beneficial to have weights of	
	donors offered from overseas in the next report, as rejection rates	
	will help inform decisions re: transplantation of small recipients.	
3.2.4	AP10, Conflict in using smaller donor organs in MV recipients and	A Butler / H
	for paediatric hepatoblastoma patients - Clarity is needed around	Vilca-
	the definition of 'small' donor organs. The suggestion is if the	Melendez
	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. ACTION: A Butler to liaise with H Vilca-Melendez and R Prasad	
	(Leeds) re: a virtual meeting to discuss this.	
3.2.5.1	AP17, Review of Cytomegalovirus (CMV) and Epstein Barr virus	R Baker
0.2.0.1	(EBV) infections in Intestinal transplantation UK wide experience –	I Bakoi
	(17.3.21) - incidence, outcome and strategies - A Butler contacted	
	A Clarkson regarding inconsistent reporting of EBV status. 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. It was agreed at the	
	Retrieval Advisory Group that when a potential bowel donor is	
	identified, if EBV testing cannot be done at the local allocated	
	centre, the sample will be sent to a separate centre that can do the	
	testing. R Baker agreed to follow this up. EBV does not appear to	
	be such an issue for paediatric patients.	
2252	ACTION: R Baker to follow this up There is a 20% incidence of post-transplant lymphoproliferative	S Watson
3.2.5.2	disorder (PTLD) in Addenbrookes' cohort and some patient deaths	S Watson
	with untreatable PTLD. Several have been PTLD in the graft from	
	the recipient indicating donor negative recipient positive is as risky	
	as donor positive recipient negative. There has been an 10%	
	incidence at Oxford and a request on PTLD rates will be requested	
	from each centre for the national forum on 28 February. S Watson	
	mentioned that NHSE has been having discussions about use of	
	Tabelecleucel to treat PTLD caused by EBV. If this goes through	
	NICE it would be used post-transplant. It was agreed that centres	
	would like to know the cost and to be involved in any conversations	
	about use of this drug.	
0.00	ACTION: S Watson to liaise with A Butler as talks progress.	001401 575
3.2.6	AP18 - Use of CMV positive donors in CMV negative patients – G	COMPLETE
	Gupte reported that the use of CMV positive donors for intestinal	
	transplant patients is not restricted for paediatric patients. There is	
	low incidence of CMV in the transplant population with effective use of IV ganciclovir for the first two weeks followed by	
	valganciclovir. Adult centres however, have had different	
	experiences:	
	Kings have not experienced incidents with CMV	
	Tangs have not expenenced incluents with Civiv	

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	 Oxford does not transplant where's there a mismatch following a patient death due to a mutation following transplant and becoming ganciclovir resistant. Cambridge changed policy in 2014 after some difficult CMV cases including resistance and now do not transplant positive donors into CMV negative recipients. However, EBV is becoming more problematic which may result in a change of policy with a different strategy for prophylaxis. There are also anti-virals now that work differently. It was agreed that the different experiences of adult and paediatric centres and immunosuppression regimes would be discussed at the national symposium in February. 	
3.2.7	COVID-19 positive donors – D Manas reported that the policy is now less restrictive and it is a clinical decision whether COVID positive donors are used. Only patients dying of COVID are excluded. There has been no transmission of COVID in any solid organs except for 3 lung transplants where the virus was transmitted to the recipients. While small bowel is not a primary infected organ, PCR is often present in the stool and can continue for some time. It is therefore a clinical decision regarding use of the graft.	COMPLETE
3.2.8	Governance – This action arose due to an incident where the weight of a young donor was incorrectly recorded, and it was noted a regular issue appears to be inaccurate estimated weights that are very different from actual weight, particularly for the adult population. The logistical problems of getting an accurate weight for a donor were noted. It was suggested that bioimpedance machines are trialled in a couple of centres to get measurements and it was agreed that this should be put forward as a formal study through the Retrieval studies. ACTION: A Butler will raise this with I Currie.	A Butler
3.2.9	Patient survival after intestinal transplantation – MCTAG(22)02 – A 2 hours virtual meeting to define measures for graft failure was not possible due to clinical commitments. The issues to be discussed were eg: Need for PN in 28 days – Yes/No	P Allan / L Sharkey / J Hinds / G Gupte See also Item
	 Expected irreversibility at 3 months Explant Relisting for transplant. It was agreed that P Allan, L Sharkey, J Hinds and G Gupte will draft a proposal for further discussion and agreement at the national forum. 	7.2
3.2.10	 UK Joint intestinal rehabilitation meeting – J Hinds reported: 3 successful joint intestinal rehab meetings have taken place to date with 80 attendees from across the UK from transplant and intestinal rehab centres. Complex cases are discussed with an academic MDT or discussion/advice going back to centres to enable access to larger intestinal centres or rehab in a timely manner. Meetings are taking place every 4 months. For the transplant registry, decisions are needed on what data to include. For data transfer J Hinds has met the people who run the registry and data sharing agreements are needed to allow data to be shared with an international registry. It is likely that this will be rolled out via spreadsheet as an interim measure initially in the next financial year for feedback. It will be extra work and each 	

	contro poede to naminate and parage to input information	
	centre needs to nominate one person to input information onto the spreadsheet.	
3.2.11	 M&F Proposal – Potential funding for film – S Watson has had conversations with the Comms team at NHSE regarding work to raise the profile of the service. However, there has been no further action, partly due to workforce changes. Data for small bowel and other organ groups differs considerably and needs to be addressed. It was agreed that input from lay members would be helpful to ensure anything that is produced is relatable and easy to understand for an outside audience. S Kay emphasized that anything that is produced needs to reach a public audience, particularly for those having limb transplants where very few patients are under medical care. ACTIONS: D Manas will contact Transplant TV who have made films on living donation and liver donation for NHSBT. 	S Watson / D Manas / C Jones / I Amin / S Kay / S Hill
	Any film will need input from patients, lay members	
	and clinicians, a script needs to be written and there needs to be a meeting with the film makers.	
	 C Jones agreed to help with this from the lay members' 	
	and public perspectiveI Amin and S Kay offered to help from a clinician's	
	perspective and S Hill will participate for paediatrics.	
	S Watson will set up a meeting	
3.2.12	Formal cessation of post-transplant monitoring forms - MCTAG(22)07, MCTAG(22)08, MCTAG(22)09, MCTAG(22)10,	Ongoing
	MCTAG(22)11 – S Peacock has sent through requirements for	
	centralizing this service. The cost would be c.£200K for a clinical	
	scientist, 2 x BMS and support staff. From an NHSE perspective,	
	one possibility is to make a business case for funding to centralise the service within one unit. However, this would be a hard sell	
	given testing is felt to be a requirement. It was agreed that GVHD	
	for adults had not been experienced without chimerism and a long	
	turnaround for results affects immunosuppression regimes. It is proposed that:	
	Centres are asked what they do currently	
	Costs are determined to provide the service locally or	
	centrally (in one or more centres)	
	 Each centre to discuss with GLH what can be provided for turnaround 	
	 Assessment is needed to see if this can fit into an existing service 	
	 Assessment of additional workforce needs and how much this would cost is needed 	
	 A formal specification of requirements and contact with labs 	
	to see if there is interest to do the work is needed.	
	 S Watson to get in touch with commissioners for the GLHs regarding turnaround times 	
	 A formal tender will be put forward to NHSE / NHSBT 	
	offering this as an essential on call acute service that could	
2 2 42	serve the liver community as well.	COMPLETE
3.2.13	Review of MCTAG guidelines for HLA Ab screening – MCTAG(22)12 – It is acknowledged that the guidelines are old and	CONFLETE
	it is proposed a draft of a re-write is considered. Defined MFI cut off levels has been removed. All agreed to send any comments on	
	how an approval system may work going forward to A Butler.	

3.3	<u>Matters Arising, not separately identified</u> – There were no matters arising.	
4.	Web information on intestinal and multi-visceral transplantation on the new NHSBT website for patients (https://www.nhsbt.nhs.uk/organ-transplantation/) - MCTAG(22)27	
	This paper from C Callaghan was circulated prior to the meeting. This topic has arisen because the content for bowel transplantation on the NHSBT website is very different in magnitude and sophistication from other pages for solid organs and contains much older information. There is no funding to produce the same sort of video animation available on other pages, but C Callaghan is keen to assemble a small group of 1-2 people from each centre (including paediatrics) plus lay input and patients to look at what content to include in a new iteration to bring the pages into alignment with other organs. ACTION: It was agreed to set up a fixed term working group led by L Sharkey and to include C Jones (Lay member).	L Sharkey / C Callaghan / C Jones
5.	Medical Director's Report	
5.1	New appointments: D Manas reported as follows The following new appointments/recruitment are announced: D Manas now has a new PA – Contact Abby Horne – abigail.horne@nhsbt.nhs.uk - Tel: 07385 525 004 Interviews will take place shortly for 2 people to replace Alex Manara Recruitment is ongoing for a new Chair of OTAG (Ocular and Tiggue Advisors Croup)	
5.2	and Tissue Advisory Group) Other News:	
	 Consent rates have decreased to 60% and seems to be due to a loss of confidence in the NHS (waiting times for ambulances, long waits in ICU and misunderstandings about opt out). Works is ongoing to address this. Finances – DCD Hearts is now not funded for next year, project support for ARCs has been lost and NRP is not yet funded. OUG - The report for the Organ Utilisation Group is now with the minister and awaiting final approval for publication. Support for this is needed from the clinical community. CLUs – local CLUs have not been funded although Lead CLUs are funded until April. NORS – There is a plan is to review the service as a lot of complex surgery is being pushed into the night. Flights are at a premium currently. They are difficult to get and expensive and teams are asked to compare flight times with road times before any request is made. Lung Summit – A Lung Summit is planned for 22 February 	
	to address considerable problems facing lung transplantation. BTRU is up and running Histopathology – funding the national plan is an issue currently and an interim plan is in place.	
6.	OTDT Hub Update	
<u> </u>	There have been workforce issues for the Hub recently. However, the team has worked hard to cover all the workload.	

7.	Summary from Statistics and Clinical Research – MCTAG(22)16	
7.1	The 2021-22 annual report is now available on the OTDT Clinical site. Last year there was a record 27 transplants which was a 56% increase on the year before. Contact details for all the lead statisticians are included in the paper circulated.	
7.2	Patient survival after intestinal transplantation – potential further subdivisions in future reports (malignancy v. non malignancy) - It is suggested a breakdown of malignant v. non-malignant indications is included in future reports to ensure that physicians referring patients with intestinal failure are confident they have the data appropriate for their patient. This is done in liver reports where there is a breakdown for autoimmune, alcohol, Hep C etc. It was noted that as numbers are likely to be small, use of the international registry could be useful as there would be a bigger data set, although it is noted that long term data sets can be unreliable in many countries. It was agreed to break down the report into indications and organ transplanted. ACTION: C Brown to provide a report with breakdowns for information only for group to assess.	C Brown
8.	National Bowel Allocation	
8.1	Performance report of the National Bowel Allocation Scheme – MCTAG(22)17 - The paper circulated shows the performance of the NBAS, detailing patients active on the transplant list between 1 January 2022 and 30 June 2022, a comparison of 1 year post-registration outcomes over time, median time to transplant, and prolonged registrations. In the first half of the year: • There were 31 patients on the active waiting list (24 adults, 7 paediatrics) • 13 of these have resulted in a transplant • Since the introduction of the scheme, in the first 2 years there has been a non-significant increase in the number of patients transplanted within 1 year of listing and a decrease in the number of deaths within 1 year of listing. • However, in the most recent period there has been an increase in deaths with 11 deaths recorded. Overall, the proportion of deaths pre-NBAS compared to the whole period after is not significantly different. Full results are shown in the report circulated and the group is asked to notify C Brown of any data amendments. It was noted that donors for paediatric patients need to be under 20 kg and this can affect the amount of time they need to remain on the waiting list. Concern was also expressed at the numbers of increasing deaths while on the waiting list and whether other options (eg DCD donors) should be considered to help improve waiting list numbers.	
8.2	Disproportionate waiting time for liver and bowel patients compared to a liver patient only — It is noted there is cohort of recipients being placed below super urgent and hepablastoma and above MV. Donors need to be a specific size and of good quality for MV transplant which is not necessarily the case for liver recipients and donors. This is now having an impact on MV outcomes, particularly for paediatric recipients. ACTION: A Butler to ask the Liver Advisory Group to consider prioritizing or categorizing access to the small donors for MV	A Butler

	and setting a threshold for donor age for ACLF rather than for MV.	
8.3	Discussion re: potential changes to allocation policy - MCTAG(22)18 – This document was created some time ago when there was little data supporting the way in which points were allocated for intestinal transplantation. It is agreed to revisit the policy now there is more information and data so that patients are not disadvantaged by what is still in place. Input from lay members will help with updating the policy. ACTION: A Butler to ask C Watson to lead a fixed term working group with 1-2 representatives from all centres and C Jones and A Wrigley (lay members) to update the policy.	A Butler
9.	Service Review Discussion	
9.	Intestinal transplantation is now well developed but there are no opportunities for peer review or CUSUM. It was agreed that it would be appropriate for the group to consider what the service should look like at a national level. It was agreed: • An up-to-date SLA is needed outlining KPIs and the requirements of the service, what a functional MV service should have, where is a unit deficient, workforce planning, strategy for 5 to 10 years. • Assessment of where units demonstrate good practice or are not able to achieve their own aims/targets is needed. • Assessment by an external body that measures the unit against the SLA is needed It was noted that issues identified in the past may not be the same now. Patients are accumulating and that creates new issues for teams. It was agreed that visits to each unit by the group, NHSE/NHSBT and a lay member would be helpful to identify what units are doing and where there are gaps when measured against the current SLA. ACTION: a) A Butler to contact S Watson and feedback to D Manas. b) A Butler to talk with G Gupte, P Allan and H Vilca-Melendez about setting up a short-term working group to decide how to move this forward.	A Butler / P Allan / G Gupte / H Vilca- Melendez
10.	Potential Bowel Donors – MCTAG(22)19	
	Potential bowel donors were defined as DBD donors who donated at least one solid organ for the purpose of transplantation, who met the criteria for bowel donation and whose family gave consent for bowel donation. Before November 2021, potential donors after brain death (DBD) who were aged < 56 years and weighed < 80 kg were considered for bowel donation. From 1 November 2021, potential DBD donors aged < 60 years and weighing < 90 kg are considered for bowel donation. • In 2021/22 of 784 UK DBD donors, 284 (36%) met the criteria for bowel donation. Of these, consent was given in 244 (86%) donors. • 27 of 189 offered (14%) were accepted for transplantation. • There was a large decrease in the number of DBD donors between 2019/20 and 2020/21 due to the pandemic. The number of DBD donors increased by 2% in 2021/22. • Consent rate remained at 86% but both offered and	

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	 Of 162 bowels offered and declined, only 4 (2%) were from donors weighing < 50 kg which were declined for a variety of reasons. Of 284 donors meeting potential bowel donor criteria, 4 (1%) weighed less than 30 kg. One was offered and declined, and 3 were offered, accepted and the bowel was transplanted. 12 non-UK donors were offered to the UK for bowel donation in 2021/22 but all were declined. Full results are shown in the report circulated. The drop off in consent and offering rates was noted as well as non-acceptance rates of those organs that are being offered. The group compromised most are paediatrics as there are not many donors. 	
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11.	Group 2 Bowel Transplants – MCTAG(22)20	
	There were no Group 2 patient intestinal transplants performed in the UK between 1 February 2022 and 31 August 2022. There was one Group 1 non-UK resident EU patient intestinal transplant in the time period.	
40	Undete realized Transplantation MCTAC(22)20	
12.	Update re: Hand Transplantation – MCTAG(22)28 S Kay stated that transplants in 8 patients have now been	
	completed. The most concerning recent development has been a decline in renal function for post sepsis patients with one patient now on dialysis with the pre-transplant GFR appearing to be a poor prognosticator for this complication. Work is ongoing to develop a protocol to address this problem and to look at synchronous kidney transplant (versus metachronous), and options for reducing the nephrotoxicity of the immunosuppressive regimen. Consent information has also changed due to these developments. Lower numbers of donor offers are also causing long waits for patients hoping for transplants and staffing is also problematic.	
13.	Update on Uterine Transplantation	
	P Friend stated that this programme is now live in Oxford being led by Isabel Quiroga and the joint relationship between Oxford and Imperial is working well. There is one person waiting for a live DBD transplant but there have not yet been any suitable offers and a living donor pair is also being considered. There have been some immunological anxieties about pre-formed antibodies. Another 4 women are going to be seen over the next couple of months. There is a potential for renal impairment, so the plan is that any transplant is short term with the uterus being removed after 1-2 pregnancies to allow the patient to come off immunosuppression. Transgender transplantation has not yet been considered. It was suggested that Richard Smith and Isabel Quiroga come to a future meeting to discuss the protocol and some of the ethical considerations. ACTION: P Friend to contact A Wrigley regarding ethical considerations for uterine transplantation.	P Friend / A Wrigley
14.	Potential Routine Inclusion of contrast enhanced CT scan in	
14.	Donor Characterisation	
	Donor imaging using CT in circumstances where a modified MV graft is being considered to minimise delays and inappropriate travel for retrieval teams and recipients, particularly where it is clear a bowel will not be used for anatomical reasons was discussed at the Retrieval Advisory Group. A small working group	

	of RAG will discuss this involving I Currie/M Berman, SNODs and	
	CLODs.	
15.	Transfer of UK intestinal data to the international transplant registry (ITR)	See Item 3.2.10
16.	SENTINEL study - MCTAG(22)21	
101	H Giele was unable to attend the meeting but the papers below were circulated for information on the study.	
16.1	SENTINEL Study Promotional Information - MCTAG(22)22 – circulated for information	
16.2	SENTINEL – Patient Information – MCTAG(22)23 - circulated for information	
16.3	SENTINEL – Informed Consent Stage 1 – MCTAG(22)24 - circulated for information	
16.4	SENTINEL – Informed Consent Stage 2 – MCTAG(22)25 - circulated for information	
17.	Increase in waiting list deaths	See Item 8.1
18.	Increase in waiting list time for liver containing grafts to 250 days	See Item 3.2.1
19.	Ethnicity of Recipients	
	L Sharkey stated that 93% of intestinal recipients are white. It was agreed that all units need to be mindful of this and that this is currently due to the referral pattern rather than decision making within the units. It was agreed that MCTAG will check this on a regular basis against unit referral patterns and national population levels.	
20.	Update from Working Groups	
20.1	Quality of Life Working Group: data collection. The following updates were given.	
20.2	Adults – P Allan reported that it has been agreed to add in PIN IQ questions to the qualitative questionnaires. The company behind the license agreement to use the PIN IQ for patients are keen for these to be used to compare patients on home PN to patients on intestinal transplant journey. ACTION: P Allan to present preliminary data of results for patients will be presented at the next MCTAG meeting to enable this to be rolled out more widely.	P Allan
20.2	Paediatrics - C Bambridge was not able to attend the meeting but reported that a clinical psychologist is now in post who may be interested in driving this plan forward. It was agreed at MCTAG that a national plan is now needed and that a deadline should be set to move this issue forward. It was also noted that quality of life has moved up the agenda in all transplant groups and that at LAG survival data is not the only marker for success. It was agreed that at the next MCTAG meeting there will be a definite decision regarding which quality of life measures will be followed for adults.	
21.	Update on NASIT	
	This was not discussed at the meeting.	
22.	Establishment of a centralised facility for chimerism testing	

	It is noted that there are benefits in both meeting face and face and	
	virtually. To enable patients to continue to move speedily through	
	the system, no changes will be made at present.	
23.	Feedback from Liver Advisory Group Meeting LAG(22)(M)01 - MCTAG(22)26	
	There is agreement from the Core Group that for European patients or S2 patients access to organs is the same as category 1. Confusion is likely to arise for patients who are in neither category or who are an emergency and at what stage this becomes an elective procedure. However, there is agreement that those who are S2 will be eligible to receive organs from UK donors.	
24.	Any Other Business	
24.1	Multicentre collaborative studies and research – It was agreed to discuss multicentre collaborative studies and research at the next MCTAG meeting. One benefit is that this could enable research funding applicable to both the paediatric and adult populations which would be difficult for one unit to achieve.	
24.2	Revisit of Exploration of options regarding use of split liver transplants as part of an MVT – There is an equipment issue used to split organs in situ that would be of benefit to the paediatric population particularly. It was noted that there are very few cases that require this skill. ACTION: This will be discussed with the same group meeting re: the hepatoblastoma tier plus Raj Prasad (Leeds).	See Item 3.2.1
25.	Date of next meeting – 12 April 2023	
	There will be two meetings in 2023. Proposed dates are:	
	 Weds 12 April 2023 – this will be a face-to-face meeting 	
	 Weds 4 October 2023 – via Microsoft Teams 	