

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 23rd July 2026

09:00 – 13:50

(Remote meeting via videoconference)

AGD INDEPENDENT / NHS ENGLAND MEMBERS IN ATTENDANCE:	
Name:	Role:
Claire Delaney-Pope (CDP)	AGD independent member (Specialist Information Governance Adviser)
Dr. Arjun Dhillon (AD)	NHS England member (Caldicott Guardian Team Representative)
Dr. Jon Fistein (JF)	AGD independent member (Chair)
Vanessa Kaliapermall (VK)	NHS England member (Data Protection Office Representative (Delegate for Jon Moore))
Prof. Jo Knight (JK)	AGD independent member (Specialist Academic / Researcher Adviser)
Dr. Mark McCartney (MM)	AGD independent member (Specialist GP / Clinician Adviser)
Prof. Matthew Sydes (MS)	NHS England member (Data and Analytics Representative (Delegate for Michael Chapman))
Jenny Westaway (JW)	AGD independent member (Lay Adviser)
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Garry Coleman (GC)	NHS England SIRO Representative
Dan Goodwin (DG)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: items 5.1 to 5.3)
Joe Lawson (JL)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.4)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
Emma Whale (EW)	Data Access and Partnerships, Data and Analytics, Transformation Directorate (Observer: item 5.5)
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Technology, Digital and Data

AGD INDEPENDENT MEMBERS / NHS ENGLAND MEMBERS <u>NOT</u> IN ATTENDANCE:	
Name:	Role / Area:
Paul Affleck (PA)	AGD independent member (Specialist Ethics Adviser)
Mr Christopher Barben (CB)	AGD independent member (Specialist Clinician Adviser)
Michael Chapman (MC)	NHS England member (Data and Analytics Representative)
Dr. Robert French (RF)	AGD independent member (Specialist Academic / Statistician Adviser)
Jon Moore (JM)	NHS England member (Data Protection Office Representative)
Dr. Jonathan Osborn (JO)	NHS England member (Caldicott Guardian Team Representative)
Miranda Winram (MW)	AGD independent member (Lay Adviser)

1	Welcome and Introductions: The AGD Chair welcomed attendees to the meeting.
2	Review of previous AGD minutes: The minutes of the AGD meeting on the 16 th July 2026 were reviewed and were agreed as an accurate record of the meeting.
3	Declaration of interests: Prof. Jo Knight noted a professional link to the lead applicant of NIC-801801-V8J7B as part of her role within Lancaster University. It was agreed that Prof. Knight would not be part of the discussion for this application and left the meeting for this part of the agenda. Prof. Matthew Sydes noted a previous professional link to the Chief Investigator of NIC-793494-K7F4Z (London School of Hygiene and Tropical Medicine). It was agreed this did not preclude Prof. Sydes from taking part in the discussion about this application. Prof. Matthew Sydes noted a professional link to University College London, but noted no specific connections with the application (NIC-758591-Z7W0W), or staff involved, and it was agreed that this was not a conflict of interest.
4 BRIEFING PAPER(S) / DIRECTIONS:	
4.1	Title: Outcomes and Registries Programme – National Major Trauma Registry (NMTR) for NHS Wales Data Protection Impact Assessment (DPIA) Previous Reviews: The ‘National Major Trauma Registry (NMTR) for NHS Wales Request 2024’ was previously discussed at the AGD meeting on the 13th June 2024. The Trauma Audit and Research Network (TARN) is an established national clinical audit for trauma care across England, Wales and the Republic of Ireland and supports 218 trauma

	receiving trusts (6 in Wales; 170 in England) by providing each trauma unit with case mix adjusted outcome analysis, performance of key process measures and comparisons of trauma care. TARN has been owned since 1988 by the Academic Health Science Centre at the University of Manchester (UoM), supported by s251 approvals for the processing of confidential patient information. Following a UoM strategic review, responsibility for the operation of TARN has been transferred to NHS England. To facilitate this, the Secretary of State for Health and Social Care has issued NHS England with a s254 Direction under the Health and Social Care Act 2012 to establish and operate an information system to collect and analyse trauma data from trauma receiving Trusts in England. This Direction is known as the Outcomes and Registries Directions 2024. This data collection has been renamed as the National Major Trauma Registry (NMTR). Summary of discussion: AGD welcomed the finalised DPIA. 4.1.1 AGD raised a query about the application of the National Data Opt-out, and a suggestion was made for the AGD NHS England D&A Representative to confirm this; but the Group was nonetheless content for the DPIA to be included as a supporting document, as and when required.	D&A Rep
4.2	Title: Outcomes and Registries Programme 2023 – National Major Trauma Registry (NMTR) Policy level DPIA – IG20230114) Previous Reviews: The ‘Outcomes Registers and Trauma Registry / DPIA’ was previously discussed at the AGD meeting on the 14th September 2023. The Trauma Audit and Research Network (TARN) is an established national clinical audit for trauma care across England, Wales and the Republic of Ireland and supports 218 trauma receiving trusts (6 in Wales; 170 in England) by providing each trauma unit with case mix adjusted outcome analysis, performance of key process measures and comparisons of trauma care. TARN has been owned since 1988 by the Academic Health Science Centre at the University of Manchester (UoM), supported by s251 approvals for the processing of confidential patient information. Following a UoM strategic review, responsibility for the operation of TARN has been transferred to NHS England. To facilitate this, the Secretary of State for Health and Social Care has issued NHS England with a s254 Direction under the Health and Social Care Act 2012 to establish and operate an information system to collect and analyse trauma data from trauma receiving Trusts in England. This Direction is known as the Outcomes and Registries Directions 2024. This data collection has been renamed as the National Major Trauma Registry (NMTR). This DPIA assesses the risk for NHS England in collecting and processing the required data and sets out the organisational and technical controls which will be implemented to mitigate those risks. Summary of discussion: AGD welcomed the finalised DPIA and confirmed that they had no further observations or comments at this stage. The Group was content for the DPIA to be included as a supporting document, as and when required.	

5 EXTERNAL DATA DISSEMINATION REQUESTS:

5.1	Reference Number: NIC-800435-G0V2J-v0.1 Applicant and Data Controller: University of Sheffield Application Title: “Investigating the relationship between social deprivation and prostate cancer” Observer: Dan Goodwin Application: This was a new application. NHS England were seeking advice on the following points: 1. Notwithstanding the unresolved query about the data controllership, the outstanding evidence of support from the institutional ethics committee, and clarification of how the transparency standard will be met; could this qualify as a future low risk Precedent. 2. Based on the information and evidence available, would AGD accept the assertion of University of Sheffield being the sole Data Controller. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. Summary of discussion: In response to point 1: 5.1.1 AGD noted that the ‘Assessment of draft Precedent eligibility - Precedent for the approval of low-risk new applications’ had been discussed at the AGD meeting on the 16th July 2026; and had been provided to the Group as part of the review of this application. 5.1.2 AGD noted that there were a number of issues outstanding that would need to be addressed before this application could potentially proceed via a low-risk Precedent, including, but not limited to: 5.1.2.1 ensuring alignment with the NHS England DARS standard for Data Minimisation, i.e. data to be minimised by codes; 5.1.2.2 ensuring alignment with NHS England DARS Standard for Transparency; 5.1.2.3 support from the research ethics committee, with the appropriate supporting documentation provided to NHS England; 5.1.2.4 the data controllership being correctly addressed in the transparency materials; and 5.1.2.5 clarification of the time limitation of the work outlined in the application. In response to point 2: 5.1.3 NHS England advised the Group that following submission of the papers for review, there had been further engagement with the applicant on data controllership. Assurance had been provided that Queen Mary University London will only use the outputs of the analyses and do not determine the means and purpose of processing and were therefore not considered a joint Data Controller. AGD noted and thanked NHS England for the update and therefore were content with the assertion of University of Sheffield being the sole Data Controller.	
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	In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review: 5.1.4 Noting the data requested would likely have the National Data Opt-out (NDOO) applied, AGD advised NHS England to make the applicant aware of this, noting that this may impact on any potential outcomes. 5.1.5 AGD noted the importance of the study, and advised that the applicant work with the National Prostate Cancer Audit if not already so doing. 5.1.6 Separate to the application: In addition to the comments made on item 5.2 and at the AGD meeting on the 16th July 2026, AGD made a number of comments in respect of the draft low-risk Precedent, including, but not limited to: 5.1.6.1 in respect of point 1(a) (<i>is time limited</i>) and 1(b) (<i>Will deliver specific outputs within a maximum period of 3 years</i>) of the 'qualifying criteria', the Group advised that these were reviewed noting that 1(a) lacks specificity and also that they may be duplications of each other. 5.1.6.2 in respect of point 1(e) (<i>Demonstrates clear benefits to health and social care in England and Wales</i>) of the 'qualifying criteria', the Group advised that this could be removed, noting that this point would be covered under point 6 (<i>All generic data sharing standards must be met</i>). 5.1.6.3 notwithstanding the advice provided on the 16th July 2026 in respect of data controllership, AGD advised that point 1(c) (<i>has a single Data Controller</i>) of the 'qualifying criteria' is reviewed, and updated, for example, to include applications i) where there is joint data controllership for a limited number of organisations; ii) where there is an already established working relationship; and iii) where there are formal arrangements in place for this working relationship. 5.1.7 Given the points raised by the Group, the NHS England SIRO Representative noted this application could not progress via delegated authority until such time as the NHS England SIRO Representative and an NHS England senior colleague within Data and Analytics had reviewed the updated application.	
5.2	Reference Number: NIC-801801-V8J7B-v0 Applicant and Data Controller: Lancaster University Application Title: "Community Wealth Building Evaluation: Learning Lessons from Scotland (CoWBELLS)" Observer: Dan Goodwin Application: This was a new application. NHS England were seeking advice on the following points: 1. Notwithstanding the unresolved query about the data controllership, the outstanding evidence of support from the institutional ethics committee, and clarification of how the transparency standard will be met; could this qualify as a future low risk Precedent.	

2. Based on the information and evidence available, would AGD accept the assertion of Lancaster University as being the sole Data Controller.

Should an application be approved by NHS England, further details would be made available within the [Data Uses Register](#).

Summary of discussion:

In response to point 1:

5.2.1 AGD noted that the 'Assessment of draft Precedent eligibility - Precedent for the approval of low-risk new applications' had been discussed at the AGD meeting on the 16th July 2026; and had been provided to the Group as part of the review of this application.

5.2.2 AGD noted that there were a number of issues outstanding that would need to be addressed before this application could potentially proceed via a low-risk Precedent, including, but not limited to:

5.2.2.1 clarification of how the [NHS England DARS Standard for Expected Measurable Benefits](#) would be met, for example, to draw reliable results from the proposed work;

5.2.2.2 ensuring alignment with the [NHS England DARS standard for Data Minimisation](#);

5.2.2.3 ensuring alignment with [NHS England DARS Standard for Transparency](#);

5.2.2.4 support from the research ethics committee, with the appropriate supporting documentation provided to NHS England; and

5.2.2.5 the data controllership being addressed / resolved.

In response to point 2:

5.2.3 AGD advised that they were **not** persuaded by the assertion that Lancaster University is the sole Data Controller, noting the description of the work outlined being a "...*joint project with Glasgow Caledonian University and the University of Glasgow*..."; and noting the [website](#) states that "*CoWBELLS is funded by the National Institute for Health Research (NIHR) and led by Glasgow Caledonian University. Other research partners include the Glasgow Centre for Population Health (GCPH), the University of Glasgow and Lancaster University*". The Group advised that NHS England discuss this further with the applicant to:

5.2.3.1 identify the correct Data Controllers in line with [NHS England DARS Standard for Data Controller\(s\)](#);

5.2.3.2 clarify the roles of all the organisations involved with the study; and

5.2.3.3 consider seeking the views of the Data Protection Office (DPO) at each organisation, to clarify the roles of the organisations involved.

In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review:

5.2.4 Separate to the application: In addition to the comments made under item 5.1 and at the AGD meeting on the 16th July 2026, AGD made a number of comments in respect of the draft low-risk Precedent, including, but not limited to:

	5.2.4.1 noting that AGD have seen a number of applications similar to NIC-801801-V8J7B, where there are a number of work packages as part of a wider programme of work, the Group advised that NHS England consider whether this should be part of the 'inclusion' or 'exclusion' criteria; noting there may be a risk that several small work packages might in reality represent a large programme of work, which would be unsuitable for a Precedent route. 5.2.5 noting the complexity on occasions of identifying Data Controllers where there are multiple organisations involved, AGD discussed that where access was to be via the national SDE, it would seem proportionate for NHS England's approach to be, to ask the organisations involved to clarify that their DPO has made an assessment that the data controllership is accurate / correct. 5.2.6 Given the points raised by the Group, the NHS England SIRO Representative noted this application could not progress via delegated authority until such time as the NHS England SIRO Representative and an NHS England senior colleague within Data and Analytics had reviewed the updated application.	
5.3	Reference Number: NIC-468622-L9V8Z-v5 Applicant: Royal College of Physicians of London Data Controllers: NHS England, Healthcare Quality Improvement Partnership (HQIP) and Digital Health Care Wales (DHCW) Application Title: "National Hip Fracture Database (MORTALITY DATA ONLY)" Observer: Dan Goodwin Linked applications: This application is linked to NIC-10343-Z3M1B. Application: This was an amendment application. NHS England were seeking advice on the following points: 1. It is appropriate to include DHCW as a joint Data Controller into this commissioned HQIP / NHS England audit specifically when a dataset (Civil Registrations of Death) covers both England and Wales. 2. The NHS England DARS Standard for Commercial Purpose is met in relation to the pilot work, and if so whether there are additional steps should NHS England take to mitigate risk in such scenarios. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. Summary of discussion: In response to point 1: 5.3.1 AGD advised that whilst they noted that DHCW wanted to be a joint Data Controller, and would ordinarily commend organisations for wanting to take responsibility for the data, noted that this was slightly different, in that the justification for the joint data controllership did not align with UK General Data Protection Regulation (UK GDPR). The Group advised that DHCW provide a clearer justification why they consider themselves to be a joint Data Controller in line with NHS England DARS Standard for Data Controller(s) and UK GDPR.	

	In response to point 2: 5.3.2 AGD advised that based on the information provided, the NHS England DARS Standard for Commercial Purpose does not appear to be met; and advised that the applicant undertake a more transparent assessment of the commercial interest that has been described for UCB BIOPHARMA SRL, including, but not limited to: 5.3.2.1 clarification of any scientific value of including pelvic fractures to UCB BIOPHARMA SRL; 5.3.2.2 including for transparency the fact that UCB BIOPHARMA SRL manufacture an osteoporosis drug; 5.3.2.3 assessing the balance between the public versus commercial benefit; 5.3.2.4 clearly stating the access UCB BIOPHARMA SRL have to the outputs; and 5.3.2.5 further information on the 'reputational benefit' for UCB BIOPHARMA SRL referred to in the internal form / application. 5.3.3 AGD queried the reference to "<i>AIMES Grid Services</i>" in one of the supporting documents provided (SD4), and noting that this company is no longer in operation, advised that NHS England discuss this further with the applicant. In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review: 5.3.4 Separate to the application: AGD noted that access was not in the national secure data environment (SDE) as this was not currently considered feasible for this audit project; and advised that it would be helpful for an update on the current NHS England position on national audits commissioned by HQIP and NHS England at a future AGD meeting, noting that work was in progress to determine whether it would be possible to provide access to data, rather than disseminations for such projects. 5.3.4 Given the points raised by the Group, the NHS England SIRO Representative noted this application could progress via delegated authority to NHS England's Data Access Request Service (DARS) once the AGD advice has been addressed.	SIRO Rep
5.4	Reference Number: NIC-793494-K7F4Z-v0 Applicant and Data Controller: London School of Hygiene and Tropical Medicine Application Title: "Understanding how cancer treatments affect multiple organ systems throughout survivorship, through analysis of large-scale data resources from England" Observer: Joe Lawson Application: This was a new application. NHS England were seeking advice on the following points: 1. There is sufficient assurance that the requested datasets, date ranges and cohort size are proportionate and appropriately data-minimised, given that this is a themed research programme and future individual analyses are not yet defined in granular detail.	

	2. The controls on future use are sufficient given the scale of data requested (the national adult cancer survivor cohort, requested datasets and date ranges, and the longer HES APC lookback to 1997/98 for baseline comorbidity ascertainment). Should an application be approved by NHS England, further details would be made available within the Data Uses Register. Summary of discussion: In response to point 1: 5.4.1 AGD discussed the nature of the programme that is being proposed, and whilst noting it is very broad with commendable ambitions, advised that whilst access to the data would be in the national Secure Data Environment (SDE), the data requested had not been sufficiently justified in the internal form / application provided. Noting that the research questions were not clearly defined, and that the limit was approximately three to five studies per year, the Group advised that: 5.4.1.1 the applicant provide further clarity on the rollout of the proposed programme of work; and 5.4.1.2 how this impacts on the data access. 5.4.1.3 the applicant consider whether there could be a six-month scoping exercise, to identify the projects that may be taken forward, including, but not limited to, identifying data that may / may not be required to support these projects, in line with NHS England DARS standard for Data Minimisation. In response to point 2: 5.4.2 AGD advised that, noting this programme may progress to a wider remit of work in the future, that controls to support this would not be in line with other similar applications, for example there was proposed to be just one Principal Investigator taking final responsibility authorising access to the data. The Group therefore advised that if advice point 5.4.1.3 is not followed, then NHS England engage with the applicant, to ensure that more robust governance processes were in place to mitigate data access, including, but not limited to, a data access committee that considers: 5.4.2.1 what data is processed per project; 5.4.2.2 that the project is 'in scope' in line with the exclusion criteria outlined in section 5a(v) (<i>what purposes can the data not be used for</i>) of the internal form / application; and 5.4.2.3 the benefits of proposed projects in line with NHS England DARS Standard for Expected Measurable Benefits. 5.4.3 AGD also advised that other governance controls that should be considered by the applicant and included are: 5.4.3.1 regular reporting on the outputs and benefits; 5.4.3.2 ongoing patient and public involvement and engagement (PPIE) to ensure that any processing of the data is in line with patient expectations; and	
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	5.4.3.3 technical controls for each project, to ensure that individuals accessing the data, only have access to the data that is relevant to the specific projects they are working on, in line with NHS England DARS standard for Data Minimisation In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review: 5.4.4 AGD noted that risk stratification tools will be developed under this application, and advised that the applicant provide further clarity of this, including, but not limited to, how this would be used in practice and any regulatory implications, noting that as currently described, the intention appeared to be to develop a clinical risk identification tool, rather than an analytical tool at a population level. 5.4.5 Given the points raised by the Group, the NHS England SIRO Representative noted this application could not progress via delegated authority until such time as the NHS England SIRO Representative and an NHS England senior colleague within Data and Analytics had reviewed the updated application.	
5.5	Reference Number: NIC-758591-Z7W0W-v0 Applicant: University College London (UCL) Data Controllers: UCL and Great Ormond Street Hospital NHS Foundation Trust (GOSH): Application Title: “BOOST Study: Better Outcomes for deaf children: Optimising and Targeted interventions for children with hearing loss (HL) in a population with newborn screening” Observer: Emma Whale Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 21st May 2026. Application: This was a new application. NHS England were seeking advice on the following points: 1. There are sufficient controls in place around downloading of record level data from ICR servers. 2. Whether the previous AGD advice has been appropriately addressed. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. Summary of discussion: In response to point 1: 5.5.1 AGD advised that there are sufficient controls in place around downloading of record level data from ICR servers. In response to point 2: 5.5.2 AGD noted and commended NHS England and the applicant, on the consideration / responses to the points raised by the Group on the 21st May 2026.	

	5.5.2 AGD noted the updates to the transparency materials, as previously suggested by the Group; however, advised that the transparency materials should be updated further to be clear that in line with the National Data Opt-out (NDOO) policy, the NDOO will not be applied, noting that the data is pseudonymised. In addition to their advice on the specific points raised by NHS England, AGD made the following observations on the application and / or supporting documentation provided as part of the review: 5.5.3 Given the points raised by the Group, the NHS England SIRO Representative noted this application could progress via delegated authority to NHS England's Data Access Request Service (DARS) once the AGD advice has been addressed.	
6 INTERNAL DATA DISSEMINATION REQUESTS:		
<i>There were no items discussed</i>		
7 EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
7.1	Reference Number: NIC-689512-S9R2Q-v1.4 Applicant and Data Controller: Nottingham University Hospitals NHS Trust Application Title: "Real World Outcomes for T- and NK-cell lymphomas in England using National Cancer Registration and Analysis Service Data (ODR2021_180)" The SIRO approval was for a two-year extension. Outcome of discussion: AGD noted that the NHS England SIRO had already provided SIRO approval on the 8th July 2026 and confirmed that they were supportive of this. AGD thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided. The NHS England SIRO Representative thanked AGD for their time.	
8 OVERSIGHT AND ASSURANCE		
<i>There were no items discussed</i>		
9 AGD OPERATIONS		
9.1	AGD ways of working The AGD Chair advised the Group, that as discussed at the AGD plenary meeting on the 18th June 2026, the 'AGD Ways of Working' and the 'AGD Team Charter' documents, had received a further review by AGD members / delegates, and were now ready for finalising / circulation. In respect of the 'AGD Themed Questions', the Group were advised that, following a discussion on this document with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency, and Trust, this would require further updates, and an update would be provided in due course. AGD were also advised that the updated draft 'AGD Terms of Reference' were currently with Jackie for review and that further update would be provided in due course.	

9.2	AGD Annual Report 2025/26 As noted at the AGD meeting on the 9 th July 2026, the AGD Chair advised the Group that the proposed AGD Annual Report 2025/26 had been discussed with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency, who was giving this further consideration. It was noted that a further update would be provided in due course.	
9.3	AGD Stakeholder Engagement The AGD Chair noted to the Group that they had met with Jackie Gray, Director of Privacy and Information Governance, Privacy, Transparency, and Trust following the last update at the AGD meeting on the 18 th June 2026; this was in line with clause 9.2 of the AGD Terms of Reference that states: “ <i>The Chair and the Deputy SIRO shall meet at least every six months to review the operation of the Group</i> ” (please see items 9.1 and 9.2 for further information).	
9.4	AGD Project Work <i>There were no items discussed</i>	
10 Any Other Business		
10.1	Dr. Robert French The Group noted that Dr. French has left AGD. AGD and NHS England colleagues wished to extend their sincere thanks for his significant contributions over the last four years during his tenure on IGARD and AGD.	
10.2	NIC-787221-X3M8G Swansea University AGD Secretariat advised the Group, that following ratification / publication of the minutes from the AGD meeting on the 25 th June 2026, NHS England had queried point 5.7.3; and that following review, it had been determined that the minutes would need updating / re-publishing to ensure that the point discussed was accurately reflected. AGD members agreed this was necessary due to there being an erroneous ‘not’ in the wording that reversed the intended meaning of the advice.	
10.3	Data Security and Protection Toolkit (DSPT) The NHS England SIRO Representative advised the Group that work was ongoing in NHS England on the DSPT for organisations that have submitted them; and that a further update would be provided in due course at a future AGD meeting.	SIRO Rep
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.		