

Profession Advisory Group (PAG) – Meeting Minutes

Tuesday, 22nd September 2026

09:00 – 10:35 / 14:00 – 15:50

(Remote meeting via videoconference)

PAG MEMBERS IN ATTENDANCE:

Role:

GP Representative from the British Medical Association (BMA)

GP Representative from the Royal College of General Practitioners (RCGP)

NHS ENGLAND STAFF IN ATTENDANCE:

Name:	Role / Area:
Narissa Leyland	PAG Chair
Karen Myers (KM)	PAG Secretariat, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
Terry Service (TS)	PAG Deputy Chair
Vicki Williams (VW)	PAG Secretariat, Privacy, Transparency and Trust (PTT), Technology, Digital and Data

PAG MEMBERS NOT IN ATTENDANCE:

Role

GP Representative from the Royal College of General Practitioners (RCGP)

1	Welcome and Introductions: The PAG Chair welcomed attendees to the meeting.
2	Review of previous PAG minutes: The minutes of the PAG meeting on the 15 th September 2026 were reviewed and were agreed as an accurate record of the meeting.
3	Declaration of interests: There were no declarations of interest
4. EXTERNAL DATA DISSEMINATION REQUESTS:	

4.1	NIC Number: NIC-812471-W5K3Y-v0 Applicant Organisation: University of Oxford OpenSAFELY Ref: AOS-2026-1043 Application Title: Mortality in Intellectual Disability and Epilepsy Outcome Points: the Group supported the application which was in line with the NHS OpenSAFELY Data Analytics Service Pilot Directions 2025 See Appendix A	
4.2	NIC Number: NIC-812473-M6X9P-v0 Applicant Organisation: University of Oxford OpenSAFELY Ref: AOS-2026-1047 Application Title: VTE risk before and after hospital admission Outcome Points: the Group supported the application which was in line with the NHS OpenSAFELY Data Analytics Service Pilot Directions 2025 See Appendix B	
4.3	NIC Number: NIC-812480-M9P4P-v0 Applicant Organisation: King's College London OpenSAFELY Ref: AOS-2026-1051 Application Title: Evaluation of the introduction of patient-initiated care and associated outcomes in rheumatology - the TailOR project Outcome Points: the Group supported the application which was in line with the NHS OpenSAFELY Data Analytics Service Pilot Directions 2025 See Appendix C	
4.4	NIC Number: NIC-812482-K4N8G-v0 Applicant Organisation: London School of Hygiene and Tropical Medicine OpenSAFELY Ref: AOS-2026-1064 Application Title: Real world use and safety of denosumab in advanced CKD and renal replacement therapy Outcome Points: the Group were supportive of the application which was in line with the NHS OpenSAFELY Data Analytics Service Pilot Directions 2025, only if the relevant datasets, in this instance, renal registry data, was in OpenSAFELY. If the renal registry data was not in OpenSAFELY then not all the necessary information was available to make a full assessment. See Appendix D	
5. WIDER PROFESSIONAL INSIGHT		
5.1	Applications where there are similar research topics / subject areas	

	It was agreed that further discussion was required, however it was still too early in the pilot process to assess presently. Noting the discussion at PAG on the 19th May 2026 around emerging demands and outlining of prioritisation methodology (item 5.2) and the outstanding action for NHS England to provide a copy of the list of strategies and action plans used as part of the assessment, it was agreed to invite Nin Sandu to a future PAG meeting to provide an update. ACTION FOR PAG SECRETARIAT: to invite Nin Sandhu to a future PAG meeting to provide an update on emerging demands and prioritisation methodology.	Sec
5.2	PAG Ways of Working review	
a)	OpenSAFELY Project Application Form PAG provided some feedback on the application form for consideration by NHS England.	NL/TS
b)	PAG Feedback Form – OpenSAFELY PAG provided some feedback on the feedback form for consideration by NHS England.	NL/TS
c)	PAG Process Map It was agreed that this item would be discussed at a future PAG Meeting ACTION FOR PAG SECRETARIAT: to add to the internal PAG forward planner for discussion at a future PAG Meeting	Sec
d)	Profession Advice – finalised document review Due to time constraints this item was not discussed and agreed to be discussed at the next meeting of PAG. ACTION FOR PAG SECRETARIAT: to include on the 29th September 2026 meeting agenda.	Sec
e)	PAG Terms of Reference (ToR) Due to time constraints this item was not discussed and agreed to be discussed at the next meeting of PAG. ACTION FOR PAG SECRETARIAT: to include on the 29th September 2026 meeting agenda.	Sec
6. CONFIDENTIAL ADVICE / BRIEFING SESSION		
	<i>There were no item discussed</i>	
7. Any Other Business		
7.1	National Data Opt Out (NDOO) Terry Service provided an update to PAG on the NDOO position of the applications discussed on the 8th September and 15th September 2026 and clarified the applicant's updated position in each case. It was noted that for three of the applications the NDOO had been applied when, on reflection with further emphasis on the absence of a legal requirement, the applicants recognised that it need not be	

	applied, and for one of the applications the applicant had provided a robust justification as to why the NDOO should be upheld. PAG thanked Terry and the applicants for their timely response to the action. PAG noted a number of outstanding actions in relation to the NDOO and agreed to discuss these at the 29th September 2026 meeting as part of the wider discussion around the PAG Action Log review.
Meeting Closure As there was no further business raised, the PAG Chair thanked attendees for their time and closed the meeting.	

Profession Advisory Group (PAG)

Feedback Form – OpenSAFELY

Meeting Details		
PAG advice sought by NHSE:	11/09/2026	
Date of PAG advice:	22/09/2026	
Application Details		
NIC Reference:	DARS-NIC-812471-W5K3Y-v0 OpenSAFELY Ref: AOS-2026-1043	
Application version Number:	V0	
Applicant Organisation:	University of Oxford	
Application Title:	Mortality in Intellectual Disability and Epilepsy	
Attendees		
Representing Organisation	Name	Role
British Medical Association (BMA)		BMA Representative
Royal College of General Practitioners (RCGP)		RCGP Representative
Declarations of Interest		
There are no declarations of interest		
Advice Required		
OpenSAFELY Application		
The OpenSAFELY Data Analytics Service Pilot Direction 2025 states: The purpose of accessing the data is to establish a secure analytics service using the OpenSAFELY platform, for users approved by or on behalf of NHS England, to run queries on GP and NHS England pseudonymised patient data.		
1a. Does this application meet the requirements of the OpenSAFELY Direction?		
Yes		
1b. Is this request in line with the following purposes as specified in the OpenSAFELY Requirement Specification? NHS OpenSAFELY Data Analytics Service Pilot Directions 2025 - NHS England Digital		

- ☐ Clinical audit
- ☐ Service evaluation
- ☐ Health surveillance
- ☒ Research
- ☐ Evaluation of the service
- ☐ Health & social care policy, planning & commissioning & public health

1c. Advice from the Profession

Supported

Supporting statement:

This study represents an excellent use of OpenSAFELY, and has good alignment to the Quintuple Aims defined by the Institute of Healthcare Improvement.

Population health and care: Good alignment. The scope of the study is focussed on a subset of the population, but the scale advantages are clear, with a realistic goal of giving meaningful information to guide the care of this cohort.

Patient experience: Not within scope

Staff experience: Good alignment. Providing effective management for those with intellectual disability is challenging, and involves difficult risk:benefit decisions such as the prescribing dilemmas the study will explore. The benefits are indirect, but welcome.

Effective use of resource: Good alignment. The primary mechanism would be through commissioning of care, education and guidance.

Advancing health equity: Very strong alignment. The population under study experiences marked health inequalities and excess mortality. The explicit focus on intellectual disability, epilepsy, deprivation, ethnicity, residential status and geographical variation places reduction of inequity at the centre of the project.

The study intends to rely on data which can be very reliably extracted from OpenSAFELY, where the comorbidities and prescribing data will be consistently recorded. The majority of the comorbidities benefit from more than 20 years of investment by the government in the GP Quality & Outcomes Framework (QOF) where the systematic creation of auditable data relating in those clinical domains was incentivised as part of contractual business processes which require the curation of high-quality data and target attainment. The effect is that England now has a wealth of consistent, standardised information which can be drawn upon.

We encourage review of the guidance we have produced on the risk:benefit of using the GP QOF code lists for this research. While the national code lists for the QOF Domains can be sensibly used for the comorbidities, the digital maturity of the core cohort list for those with intellectual disability should be focussed on for extension beyond the QOF Learning Disabilities register codes. In particular there

is a need for careful interrogation of which Inactive concepts in SNOMED CT represent the mappings from READ / CTV3. PAG notes the work done in SNOMED to inactivate older, non-conformant terms, which have been inactivated in the past 5 years. Many but not all of those codes have been retained in the GP QOF code lists.

There is an interesting issue of health equity in those who have intellectual disability but whose condition is not recognised

The consideration of public usage data in these inactive codes may be a useful adjunct.

Profession Advisory Group (PAG)

Feedback Form – OpenSAFELY

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Date of PAG advice:	22/09/2026	
Application Details		
NIC Reference:	DARS-NIC-812473-M6X9P-v0 OpenSAFELY Ref: AOS-2026-1047	
Application version Number:	V0	
Applicant Organisation:	University of Oxford	
Application Title:	Venous thromboembolism (VTE) risk before and after instances of hospital care in England: evaluation of risk trajectories and VTE prevention pathway	
Attendees		
Representing Organisation	Name	Role
British Medical Association (BMA)		BMA Representative
Royal College of General Practitioners (RCGP)		RCGP Representative
Declarations of Interest		
There are no declarations of interest		
Advice Required		
OpenSAFELY Application		
The OpenSAFELY Data Analytics Service Pilot Direction 2025 states: The purpose of accessing the data is to establish a secure analytics service using the OpenSAFELY platform, for users approved by or on behalf of NHS England, to run queries on GP and NHS England pseudonymised patient data.		
1a. Does this application meet the requirements of the OpenSAFELY Direction?		
Yes		
1b. Is this request in line with the following purposes as specified in the OpenSAFELY Requirement Specification? NHS OpenSAFELY Data Analytics Service Pilot Directions 2025 - NHS England Digital		

- ☐ Clinical audit
- ☐ Service evaluation
- ☐ Health surveillance
- ☒ Research
- ☐ Evaluation of the service
- ☐ Health & social care policy, planning & commissioning & public health

1c. Advice from the Profession

Supported

Supporting statement:

This study shows good alignment to four of the Quintuple Aims as defined by the Institute of Healthcare Improvement:

Population health and care: Strong alignment. Venous thromboembolism (VTE) remains an important cause of preventable morbidity and mortality. The study aims to improve understanding of thrombotic and bleeding risk across modern hospital pathways and may inform future approaches to prevention in large patient populations.

Patient experience: Good alignment. Better targeting of thromboprophylaxis has the potential to reduce avoidable VTE while also avoiding unnecessary bleeding complications. The outcomes under study are meaningful to patients, although patient experience is not directly examined.

Staff experience: This is not a focus of the study. Any benefits to staff would be indirect, arising through improved evidence to support thromboprophylaxis decisions and risk communication.

Effective use of resource: Strong alignment. The study seeks to evaluate whether current VTE prevention pathways are appropriately targeted and may help identify where preventative treatment delivers greatest value, particularly in newer models of care such as same-day emergency care.

Advancing health equity: Moderate alignment. The study includes analysis by deprivation, ethnicity and geography, which may identify variation in risk and outcomes. However, reducing inequalities is not the primary objective of the work.

PAG is please to support this study which offers a natural extension from the existing evidence base into the Same Day Emergency Care (SDEC) model of care, which we perceive to be growing over time, as evidence-based treatments and pathways facilitate more care being delivered outwith the traditional model of outpatient / admission pathways.

PAG notes that the changing models of care over time seem to be associated with the growth of SDEC-type services. This means the study may be in a position to comment on the observed trends over time. The validation of the information

model being used to identify SDEC may be very valuable as a re-usable artifact for future studies in OpenSAFELY.

We agree the data are likely to be available and reliable in the datasets, providing a firm basis for analysis.

The secondary goal of producing validated phenotypes is laudable, and we encourage careful documentation of the methodology and editorial decisions made in doing so, which are the key enablers that future authors will need in order to determine whether the phenotypes match the use-case well enough.

We note that NHS England already maintains SNOMED CT reference sets for various forms of major bleeding, but which are not necessarily published with the associated metadata necessary for them to be readily used.

Profession Advisory Group (PAG)

Feedback Form – OpenSAFELY

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Date of PAG advice:	22/09/2026	
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NIC Reference:	DARS-NIC-812480-M9P4P-v0 OpenSAFELY Ref: AOS-2026-1051	
Application version Number:	V0	
Applicant Organisation:	King's College London	
Application Title:	Evaluation of the introduction of patient-initiated care and associated outcomes in rheumatology - the TailOR project	
Attendees		
Representing Organisation	Name	Role
British Medical Association (BMA)		BMA Representative
Royal College of General Practitioners (RCGP)		RCGP Representative
Declarations of Interest		
There are no declarations of interest		
Advice Required		
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1c. Advice from the Profession

Supported

Supporting statement:

This study has good alignment to four of the Quintuple Aims

Population health and care: Good alignment. The study evaluates a major change in the delivery of care for people with inflammatory arthritis and seeks to understand whether patient-initiated follow-up delivers safe and effective outcomes. The findings may influence the future design of long-term condition management pathways.

Patient experience: Strong alignment. Patient-initiated follow-up is fundamentally a patient-facing redesign of care, intended to improve convenience, responsiveness and patient control over access to services. The study directly evaluates whether these intended benefits are realised and whether some groups experience unintended harm.

Effective use of resource: Strong alignment. A core objective is understanding whether routine follow-up activity can be reduced while maintaining quality of care. The study examines healthcare utilisation, outpatient demand, emergency activity and broader system impacts, making resource stewardship central to the research question.

Advancing health equity: Good alignment. The authors explicitly propose to examine demographic variation, identify which groups benefit most or least from PIFU, and assess whether implementation may inadvertently widen inequalities in access or outcomes.

Staff experience: This is not a primary focus of the study. Any staff benefits would be indirect, arising through improved understanding of how patient-initiated pathways affect workload, service delivery and clinical decision-making. PAG encourages continued consideration of workforce impacts when evaluating major service redesign programmes.

PAG is pleased to support this study, noting that the principle of PIFU is inherently appealing, and that the collaborative shared care management of patients with these conditions can be highly effective at delivering safe, effective care. The context is that musculoskeletal pathways are intensively managed by commissioning pathways, including the role of hub-based care, which can create

significant delays in patients accessing the care that they need. There is an uneasy tension therefore between commissioning and patient-led encounters, and this research will be welcome to validate whether a PIFU approach is supportable by best evidence, and may make a material difference to care provision.

NHS App and PIFU

Coding of PIFU

Profession Advisory Group (PAG)

Feedback Form – OpenSAFELY

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Date of PAG advice:	22/09/2026	
Application Details		
NIC Reference:	DARS-NIC-812482-K4N8G-v0 OpenSAFELY Ref: AOS-2026-1064	
Application version Number:	V0	
Applicant Organisation:	LSHTM	
Application Title:	Real world use and safety of denosumab in advanced CKD and renal replacement therapy	
Attendees		
Representing Organisation	Name	Role
British Medical Association (BMA)		BMA Representative
Royal College of General Practitioners (RCGP)		RCGP Representative
Declarations of Interest		
The RCGP representative previously worked as a digital clinical lead in a regional Clinical Commissioning Group which collaborated on shared care pathways with the regional metabolic bone diseases specialists, and implementation of clinical decision support tooling for General Practice such a data entry templates, population search tooling, and digital clinical decision support for denosumab safety checks. The BMA representative has no additional interests to declare.		
Advice Required		
OpenSAFELY Application		
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1c. Advice from the Profession

Supported

Supporting statement:

PAG agrees with the timeliness of the study in relation to the expiry of the market exclusivity for Denosumab, and that we would expect to see an upwards shift in prescribing over time of this drug and biosimilar treatments. This invites some reflective commentary, which we offer below.

This study has good alignment to four of the Quintuple Aims, as defined by the Institute of Healthcare Improvement:

Population health and care: Good alignment. The study rationale sets out why there is a deficit in the evidence base for this cohort, highlighting the opportunity for improving treatment decisions with the additional learning that will come from this paper.

Patient experience: Good alignment. The study focuses on outcomes that matter directly to patients, including fractures, treatment-related adverse events, hospitalisation and mortality. In particular, we note that many patients with advanced CKD have frailty, polypharmacy and require assistance with adherence to oral treatments, which contribute to the position of Denosumab in treatment regimes, as an alternative. The trade-off includes the risk of hypocalcaemia, and evidence to support understanding of how to mitigate that risk will be welcome.

Effective use of resource: Good alignment. The study may help improve targeting of treatment, identify patients at higher risk of adverse outcomes, and support evidence-based use of expensive therapies. The potential contribution to future NICE technology appraisal activity further strengthens the service relevance.

Advancing health equity: Good alignment. The authors propose examining variation in treatment use and outcomes and identifying inequalities in access to care.

Staff experience: This is not a primary focus of the study. Staff experience is often difficult to observe from the data in the records alone, but is of interest in this study.

While the data may not be extractable, the study may be in a position to consider and comment on the impact of this treatment on the professionals involved in the delivery of antiresorptive treatment.

PAG observes that qualitative differences arise in the interpersonal relationships between those who have long-term injectable treatments, and those who don't. Patients having regular injectable treatment over long periods of time gives natural opportunities for the development of relationships between patients and staff. Where the majority of treatment

is administered by a patient to themselves (e.g. taking a medication) the necessity of health care professionals in monitoring and administering treatment like denosumab creates a repeated cycle of care – the checking for safety, and the event of giving the treatment gives NHS staff an active role in the promotion of health in the individual. At a time when we observe a series of forces which are eroding continuity of care, treatment shifts have the potential to be relationship-building with benefits beyond the immediate biological effects. In context, the cohort of patients in this study can be predicted to be older patients with complex medical and social needs, where such continuity can be incredibly useful, whether that is a District Nursing team who are visiting the patient at home, or a Practice Nurse.

In addition to this, bisphosphonate therapy in this cohort creates many practical difficulties for clinicians in creating and using the data necessary to effectively manage a patient. The once-weekly antiresorptives come with significant handover issues where the effort required to educate both the patient and potentially those supporting the patient is considerable. Often patients may have limited care packages such as once-daily visits, where the requirements for an oral bisphosphonate in terms of its administration may result in the treatment being 'left out' for the patient to take later (because it cannot be taken at the same time) and may result in the treatment not being taken etc.

In terms of managing such patients therefore, to have a treatment pathway where the event of administration removes the uncertainties by having an accessible record can be very welcome to reduce the complexity of managing a patient in this cohort.

Denosumab prescribing will be influenced by regional shared care arrangements, and PAG notes that in some areas the treatment is established as being initiated by secondary care and continued by general practice, but there are areas of the country where it is considered suitable to be initiated by general practice and prescribed without secondary care involvement. This study may be in a position to observe where the 'first prescription' was created, and reflect these regional policies.

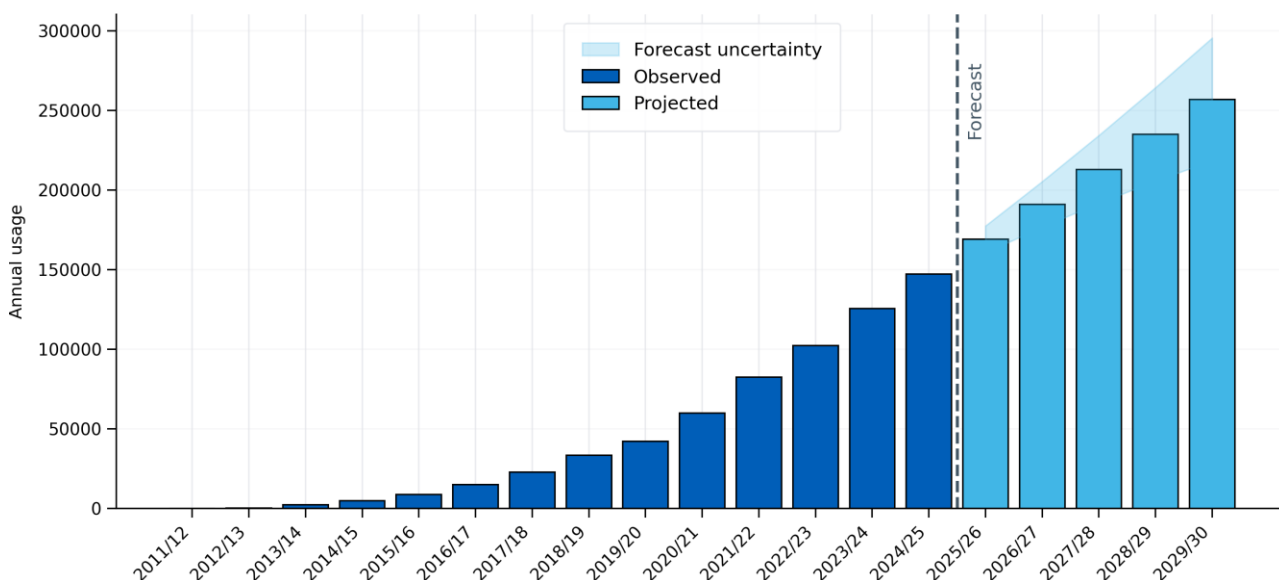
There may be patients whose specialists operate in community trusts, and where first prescriptions may be issued without appearing in the GP or hospital records. Although this may mean that prescribing data are incomplete, we anticipate the authors may be able to detect the event of administration using GP coded data, subject to those practices having recorded the event e.g. 700139004 | Denosumab therapy (procedure) |.

At present, SNOMED CT UK has not been adapted to facilitate natural and easy recording of Denosumab in pre-coordinated concepts, which creates challenges in interpreting the data. For example, Denosumab therapy (procedure) is a Defined concept in SNOMED, which includes the attribute HAS METHOD 129445006 | Administration - action (qualifier value) | but the Description itself has an ambiguity in the lexicon – the code should be used as a procedural code to record the event of administration of the drug. However, the lexical description could very easily be used by staff as the header code for the problem-orientated record, which could result in the entry of a code with Episodicity (for example in EMIS, with the code qualifier "Review" as a "Problem") which could indicate that the code instance did not reflect administration, but an encounter entry to collate the chronic disease management. This will create challenges in interpretation, particularly as an audit

of published Shared Care Record protocols finds that guidance is typically issued by clinical advice without coding advice regionally.

Review of the public code usage in GP data however, confirm that there is a clear pattern of increasing use over time, as shown in this simple graph generated by Microsoft Copilot, using the published data up to Summer 2025.

700139004 | Denosumab therapy (procedure) |



The authors may wish to evaluate the completeness and accuracy of prescribing vs coded data, and the trends in related coding, and comment on whether a national standardised data model should be created for the therapy. The Joint GP IT Committee continues to advocate for the advancement of data quality, and calls for the commissioning of a data quality improvement programme under which such work could sensibly take place.

The authors may be interested to attempt to correlate whether Denosumab data have been entered using externally authored decision support tooling, which may be reasonably inferred from the same-encounter presence of one or more of the following codes:

25721000000107 | Template entry - EHR composition type (record artifact) |
394837003 | Protocol entry (qualifier value) |

These concepts are often added to an Encounter in GP records, leaving 'breadcrumbs' that record the use of decision support tools to create an audit trail in the record. The authors may be able to make observations as to data quality differences between records where those tools have been used, and where they have not.

PAG notes the potential benefits to studies such as this in relation to the UK Renal Registry, and has recorded this in our log demonstrating the requirement, for future strategic discussions internally.

PAG encourages the authors to read the separate guidance on coding in GP data, specifically in relation to the codification of eGFR in GP data.