

Profession Advisory Group (PAG) – Meeting Minutes

Tuesday, 6th October 2026

09:00 – 10:00 / 14.00 – 15:15

(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 (NL)	PAG Chair
Karen Myers (KM)	PAG Secretariat, Privacy, Transparency and Trust (PTT), Technology, Digital and Data
Terry Service (TS)	Deputy Chair (in attendance: item 1 to 4.2)
Vicki Williams (VW)	PAG Secretariat, Privacy, Transparency and Trust (PTT), Technology, Digital and Data

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 29 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-812488-Y4C6F-v0 Applicant Organisation: Imperial College London OpenSAFELY Ref: AOS-2026-1069

	<p>Application Title: The effects of GLP-1 receptor agonists: evaluating the effectiveness, adverse and protective side-effects across diverse cohorts</p> <p>Outcome Points: the Group supported the application which was in line with the NHS OpenSAFELY Data Analytics Service Pilot Directions 2025</p> <p>Separate to the application: it was agreed that PAG would provide a paper on the challenges of interpreting externally issued medications / prescriptions and recording in the NHS GP system</p> <p>See Appendix A</p>	PAG
4.2	<p>NIC Number: NIC-812489-Q7B1W-v0</p> <p>Applicant Organisation: RAND Europe Community Interest Company</p> <p>OpenSAFELY Ref: AOS-2026-1025</p> <p>Application Title: A study of the burden of frailty and frailty-related outcomes</p> <p>Outcome Points: the Group supported the application which was in line with the NHS OpenSAFELY Data Analytics Service Pilot Directions 2025</p> <p>See Appendix B</p>	
4.3	<p>Update on application discussed at PAG on 29/09/26</p> <p>NIC Number: NIC-812484-D0F5R-v0</p> <p>Applicant Organisation: Genomics England</p> <p>OpenSAFELY Ref: AOS-2026-1066</p> <p>Application Title: Genomics England adults programme: characterising current prescribing of drugs which have pharmacogenomic guidelines and associated outcomes in the NHS in England</p> <p>Outcome Points: the Group supported the application which was in line with the NHS OpenSAFELY Data Analytics Service Pilot Directions 2025</p> <p>Separate to the application: it was agreed that the recently published 'Profession Advice – Clinical Trials' would be updated to include the position statement on feasibility.</p> <p>See Appendix C</p>	PAG
4.4	<p>Update on application discussed at PAG on 29/09/26</p> <p>NIC Number: NIC-812486-T0C2N-v0</p> <p>Applicant Organisation: Imperial College London</p> <p>OpenSAFELY Ref: AOS-2026-1067</p> <p>Application Title: Pancreatic cancer-related healthcare</p> <p>Outcome Points: the Group supported the application which was in line with the NHS OpenSAFELY Data Analytics Service Pilot Directions 2025</p> <p>Separate to the application: it was agreed that PAG would provide a paper on requirements around organisational data being brought into the OpenSAFELY platform for a specific purpose / comparator analysis.</p>	PAG

	See Appendix D	
5. WIDER PROFESSIONAL INSIGHT		
5.1	PAG Ways of Working PAG Internal Forward Planner The internal forward planner was discussed. PAG Action Log The PAG action log was discussed and updates provided on outstanding actions.	
6. CONFIDENTIAL ADVICE / BRIEFING SESSION		
<i>There were no items discussed</i>		
7. Any Other Business		
<i>There were no items discussed</i>		
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:	28/09/2026	
Date of PAG advice:	06/10/2026	
Application Details		
NIC Reference:	DARS-NIC-812488-Y4C6F-v0 OpenSAFELY Ref: AOS-2026-1069	
Application version Number:	V0	
Applicant Organisation:	Imperial College London	
Application Title:	The effects of GLP-1 receptor agonists: evaluating the effectiveness, adverse and protective side-effects across diverse cohorts.	
Attendees		
Representing Organisation	Name	Role
British Medical Association (BMA)		BMA Representative
Royal College of General Practitioners (RCGP)		RCGP Representative
Declarations of Interest		
<p>The RCGP representative has previously been in communication with the NHS England commissioners of the NHS weight loss framework, to discuss concerns raised by RCGP HIG members in relation to the possible lack of codes within SNOMED CT required to effectively record and monitor the provision of the drugs in this study in GP records.</p> <p>The BMA representative has no declarations of interest</p>		
Advice Required		
OpenSAFELY Application		
<p>The OpenSAFELY Data Analytics Service Pilot Direction 2025 states:</p> <p>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.</p>		
<p>1a. Does this application meet the requirements of the OpenSAFELY Direction?</p>		
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:

Strategic Alignment

This paper shows string alignment to the Quintuple Aims described by the Institute of Healthcare Improvement:

Population health and care: Strong alignment. GLP-1 receptor agonists are increasingly used across very large populations with diabetes, obesity and associated cardiometabolic disease. The study seeks to evaluate both beneficial and adverse effects across diverse cohorts and therefore has potential relevance to a substantial proportion of NHS patients.

Patient experience: Good alignment. Tolerability and treatment discontinuation are explicit components of the research question. The study aims to understand adverse effects, identify patients at greater risk of complications, and support better-informed treatment decisions. While patient experience is not directly measured, treatment burden and tolerability are closely related to patient experience.

Staff experience: Strong alignment. The rapidly evolving evidence base around GLP-1 therapies presents challenges for clinicians balancing benefits, adverse effects and treatment continuation. The study seeks to provide evidence supporting prescribing decisions, monitoring and management of complications, which may support professional confidence in an area of rapidly changing practice. For clinicians, the rapidly evolving society / cultural perspective is at odds with the available knowledgebase from which to counsel patients, and the constraints of the prescribing budgets which means we may not act independently in using NHS funding. This is a stressful experience, and so having good clinical information helps us to have those sometimes difficult conversations.

Effective use of resource: Strong alignment. The study explicitly aims to identify patient groups most likely to benefit from treatment and those at highest risk of

adverse effects. Given the scale of GLP-1 prescribing and associated costs, evidence supporting more targeted use has direct relevance to medicines optimisation and NHS resource stewardship.

Advancing health equity: Good alignment. The proposal specifically references exploration of effects across diverse patient groups, including people with multimorbidity, frailty, different ethnic backgrounds, pregnancy and other under-represented populations.

Commentary on GP Data

The long lookback period means that the study will find distinct periods of recording, with different data quality issues. Prior to 2018, coding was largely using Read Version 2, and the vast majority of prescriptions would have been issued through GP systems.

Over recent years, the data will all be recorded using SNOMED CT, but over the same time period, a paradigm shift in national prescribing has occurred because of the increasing use of private prescribing for obesity management.

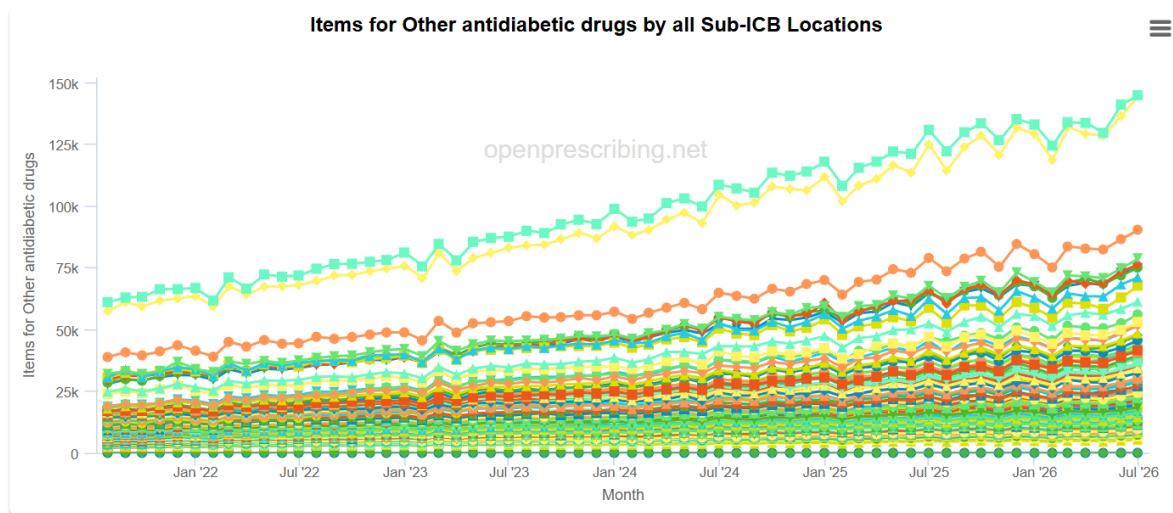
We note recent evidence from The Health Foundation which indicates significant differences in treatment with these drugs in weight loss, with imbalance in gender and socio-economic status.

<https://www.health.org.uk/reports-and-analysis/analysis/glp-1-drug-prescriptions-for-obesity>

We note survey data which quantify the scale of NHS prescribing in this space versus the private sector, which suggest 10 to 20 fold differences in the number of prescriptions being issued.

<https://www.ucl.ac.uk/news/2026/jan/16-million-uk-adults-used-weight-loss-drugs-past-year>

The data from OpenPrescribing show linear increases of Chapter 6.1.2.3 of the BNF (the GLP1s), as well as very significant regional variation, with North West and North East London ICBs having significantly higher rates, and what also appears to be an increasing divergence from other regions.



For clarity, practice graphs and maps only show standard GP practices, and exclude non-standard settings like prisons, out-of-hours services, etc.

Built with Highcharts

Figure 1 OpenPrescribing data 05/10/2026

PAG wishes to comment on the effects of this societal phenomenon on GP data, and GP workload.

Recording of private prescriptions in GP records

At present, private providers do not need to notify a patient's general practitioner of the event of prescribing a medication. A provider, or a patient may or may not inform the GP surgery.

Recording such a prescription event is time consuming, not a contractual requirement, and in GP system suppliers is likely to rely on modification of the built-in prescribing modules, which do not necessarily deliver on the requirements that would be set out for a system designed to capture externally issued prescribing. For example, a precise issue date must be recorded for each prescription (and where the date is not known, a spurious date must be entered), the dose may be adjusted, or the treatment stopped, but there is no reliable mechanism for that information being shared to ensure the GP record is Accurate.

This issue is increasing over time as the number of prescriptions issued privately increases. There are implications for GP workload from this, and it reflects a growing unrecognised and unfunded burden of responsibility. GP records are the only mechanism by which clinical safety through digitally shared prescribing records for direct care can enable these prescriptions to enter the NHS digital 'ecosystem'.

The effect of this is that GP data will include a proportion of all private prescribing, where the GP surgery was notified of the prescribing, and if they chose to record the external issuance of a prescription.

This study may be able to analyse how many private prescription issues were recorded in this way, it may be possible to compare against national estimates, to understand what percentage are being recorded in primary care records. PAG anticipates that it will be low, with considerable local and regional variations as to

how often these records are made, reflecting the lack of standardisation and potential health inequities associated with the absence of effective information sharing systems to automate the transparency of prescribing.

Historically, the number of private prescriptions being issued has been lower, and the emergence of this widespread use of clinically significant drug treatment outside the NHS is unprecedented in the UK. The safety issues arising are therefore increasing, and should prompt national policy considerations. It would be possible for prescribing standards to be agreed which could require digital transparency for the purposes of direct care, or even for secondary use.

Missing codes

In Summer 2025, SNOMED UK introduced a series of new UK concepts for the recording of adverse drug reactions in the GLP1 class, but with leaf codes only for liraglutide, semaglutide and exenatide (i.e. not all treatments).

No concepts have been introduced to enable the recording of additional context – specifically, there are no concepts for “GLP1 not tolerated” or “GLP1 not suitable” or “GLP1 declined”, which represents a missing opportunity in the ability of primary care teams to record relevant clinical findings to make the data more understandable. In turn, this means that regional shared care record systems, population health systems and research do not have the same level of rich contextual information as for some other drug treatments.

This may be valuable therefore to note in publication in policy recommendations.

END

Profession Advisory Group (PAG)

Feedback Form – OpenSAFELY

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Date of PAG advice:	06/10/2026	
Application Details		
NIC Reference:	DARS-NIC-812489-Q7B1W-v0 OpenSAFELY Ref: AOS-2026-1025	
Application version Number:	V0	
Applicant Organisation:	RAND Europe Community Interest Company	
Application Title:	A study of the burden of frailty and frailty-related outcomes	
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 has previously implemented digital solutions for the recording and audit of frailty in general practice, as a regional digital lead.		
The BMA representative has 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:

Strategic Context

Population health and care: Strong alignment.

Frailty is a major determinant of morbidity, mortality, healthcare utilisation and quality of life in older adults. With an ageing population, this is an area of major national interest.

Patient experience: Good alignment.

Earlier identification and proactive management of frailty may support better care planning and more coordinated care. Although patient experience is not directly measured, the outcomes being studied are important to people living with frailty and those supporting them.

Staff experience: Good alignment.

Frailty care frequently requires clinicians to make complex decisions regarding risk, medicines optimisation, falls prevention, hospital admission and future planning. Improved understanding of frailty trajectories and associated outcomes may support professional confidence and consistency in care delivery. In general practice, the availability of frailty support services is deterministic in our ability to deliver best care, and where the service provision does not match the demand, it causes considerable occupational stress on staff. This means rational delivery of services is strategy for our wellbeing.

Effective use of resource: Strong alignment.

The study examines healthcare utilisation, admissions, institutionalisation and other downstream consequences of frailty. The findings may support more effective targeting of service, and inform future planning of NHS and social care resources.

Advancing health equity: Strong alignment.

The study explicitly explores variation across demographic, socioeconomic and geographical groups. Given the unequal burden of frailty and associated outcomes

across the population, the work has clear relevance to identifying and addressing health inequalities.

Comments on GP Data in this area

The study may observe the introduction of the eFI score into general practice initially through the enhanced service, and later through core GMS contract requirements, although importantly, the age threshold for the recording in GP surgeries was set at 65. We therefore assume the authors may be planning to calculate eFI scores dynamically as opposed to reviewing coded eFI scores.

Recording of frailty

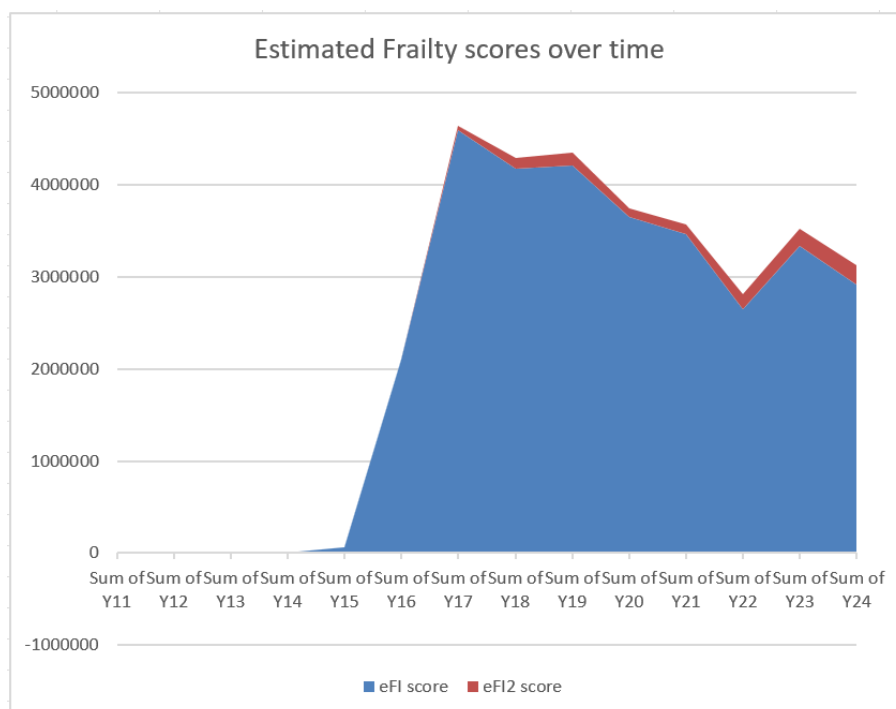
The study has important considerations to make in relation to the quantification of frailty, and how it is recorded in GP records.

PAG notes the intention to use eFI scores, but it isn't immediately clear how, and so we comment on certain potential pitfalls

Coded eFI scores

When the eFI score was introduced, it took time for the necessary guidance to be communicated effectively in general practice. The separate recording of a coded eFI score and a coded frailty diagnostic (using mild/moderate/severely frail Read codes) was a novel approach, and PAG is aware of reports that large portions of the population were recorded in batches with the attribution of a frailty code without clinical review.

Public Usage data (from the Data Migration Workbench published via TRUD) show the use of estimated frailty scores over time, which are noted to be falling progressively:



During this time period, the number of codes used to record a diagnosis of frailty, using either the semiquantitative codes for mild/moderate/severe frailty, or the quantitative frailty scores such as the Rockwood Score, have grown considerably:

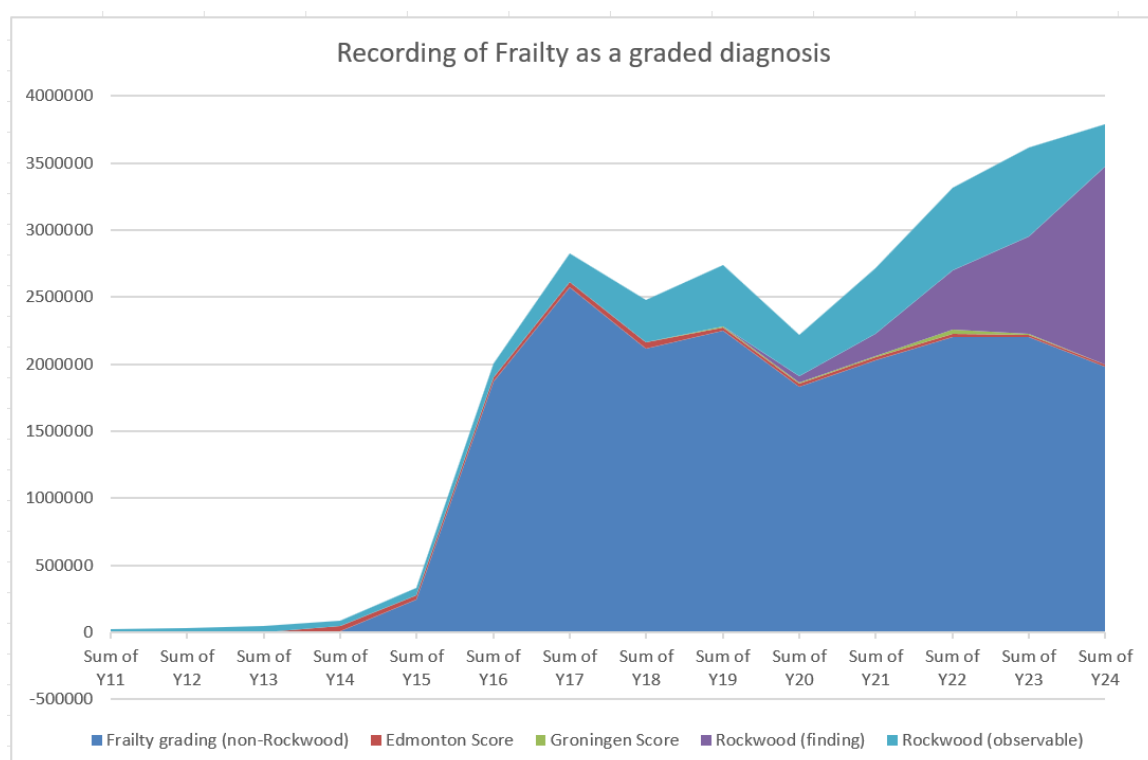


Figure 2 n.b. these are raw code counts, and the multiple codes may be used in the same patient at the same time

In 2024-2025, the Rockwood Score accounted for around half of all frailty grading.

Numerically, the 'count of' eFI scores in 2024-2025 compares approximately 3 million scores (associated with 2 million frailty diagnoses, quantified using as mild/moderate/severely frail) as compared with approximately 1.8 million entries of the Rockwood Score.

PAG notes that the GMS contractual requirements to record frailty scores are only for those aged 65 or older, and that the number of patients from age 50 to 64 (who are part of the study cohort) are likely to have very few coded eFI scores in their records.

PAG notes that the authors may be intending to calculate eFI scores rather than using coded records; the methodology is not commented on in the application.

Rockwood Score in General Practice

During the pandemic, the integration of the Clinical Frailty Index (Rockwood Score) into decision making in relation to ventilators for the frail population caused a rapid 'ripple' in the use of the score, which propagated its use into non-intensive care settings. It became used by emergency departments when prioritising admission, paramedics when making decisions to convey patients to hospital or not, and all the

way through to general practice, where GPs began to code the score. In the Oxfordshire shared care record, the item was added to ensure that GP scores were accessible to hospital teams for example. Caution should be exercised when interpreting historical code scores, because of the Alternative Maps for Observable Entities used during the READ->SNOMED migration, but the data from 2018 onwards should contain these records.

The national data show a paradigm shift – there is a rapid and accelerating growth in the use of the Rockwood Score.

PAG therefore encourages the authors to consider the presence of Rockwood Scores and mild/moderate/severely frail diagnostic codes as valuable data, possibly more valuable than eFI scores, for the purposes of the study.

Associations between eFI score, frailty grading and outcomes

The study has the potential to look at conflicting information to identify data quality issues – how many patients have inconsistent attribution of frailty that is highly inconsistent with their eFI scores? What is the difference when different professionals record frailty? With the same parameters, do different professions judge frailty more reliably? Does continuity of care impact on the accuracy of frailty determination? These questions are valuable for planning how to best identify frailty.

Policy decisions on the grading of frailty

In terms of health policy, this is an opportunity to review the accelerative increase in the use of the Rockwood Score, and consider why records in general practice are showing those increases. At present, there is no national requirement for GP supplier systems to promote the use of the score, and existing tooling delivered for the GMS contract still favours the use of Mild/Moderate/Severe frailty, which aligns easily to the eFI score.

“Canadian Study of Health and Ageing” is the current Preferred Term for the Rockwood Score in SNOMED UK, which is not in line with common parlance, and may not be the most useful way for the data to be rendered. This study may be able to comment on how often the preferred term is overridden, and consider whether SNOMED UK should be reprogrammed to prefer one term over another.

END

Profession Advisory Group (PAG)

Feedback Form – OpenSAFELY

Meeting Details		
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Date of PAG advice:	29/09/2026 AND 06/10/26	
Application Details		
NIC Reference:	DARS-NIC-812484-D0F5R-v0 OpenSAFELY Ref: AOS-2026-1066	
Application version Number:	V0	
Applicant Organisation:	Genomics England	
Application Title:	Genomics England adults programme: characterising current prescribing of drugs which have pharmacogenomic guidelines and associated outcomes in the NHS in England	
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 PAG is willing to provide advice on the associated outcomes described within the application, if the authors wish to specify them for comment.
Supporting statement:

This paper is the first application considered under the direction for the use-case of data gathering to inform study design, is therefore noteworthy, and represents a landmark.

PAG recognises the scientific opportunities arising through pharmacogenomics, and the strategic position it has in both the advancement of health care provision, and the public policy approaches which will be formed on its basis.

PAG notes that the context is also related to the feedback given by the Joint GP IT Committee in relation to the formation of the legal direction earlier this year which resulted in the reprovisioning of the GPPR dataset to Genomics England to facilitate this work:

<https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notice/secretary-of-state-directions/gpes-data-for-consented-research-directions-2026>

This, and the use of OpenSAFELY, are examples of the operational implementation of the commitment from the RCGP and BMA on behalf of general practice to facilitate the use of GP data for purposes beyond direct care, where it is done in ways which maintain the trust of the public and the profession in medical confidentiality.

Alignment of strategic aims

Pharmacogenetics and the work this OpenSAFELY project approaches has powerful alignment to the Quintuple Aims as defined by the Institute for Healthcare Improvement.

Population health and care: Strong alignment. Pharmacogenomics has the potential to influence prescribing decisions across large parts of the population. Although this project is preparatory work rather than a clinical study in itself, it aims to inform the design of a future national programme intended to improve medicines optimisation and reduce adverse drug reactions, and is known to have groundbreaking potential.

Patient experience: Good alignment. The ultimate purpose of pharmacogenomics is to help patients receive medicines that are safer and more effective for them as individuals. This study contributes indirectly by informing the design of a programme intended to improve prescribing and reduce avoidable harm.

Staff experience: Good alignment. Pharmacogenomics has the potential to improve confidence in prescribing decisions and support more personalised care. While staff experience is not directly studied, the programme seeks to generate evidence that may ultimately support clinicians in medicines optimisation and risk reduction. The effects of iatrogenic harms weigh heavily on the profession on many levels, and so evidence-based reduction in those harms is of great importance to us. General Practice is based on principles of approaching holistic care, and is likely to embrace the opportunity to advance personalised care with the additional information available through these technologies.

Effective use of resource: Strong alignment. A central objective is to understand which drug-gene pairs are likely to provide the greatest benefit and where future investment should be targeted. The study therefore directly supports efficient design of a future national programme and may contribute to reducing the substantial burden associated with adverse drug reactions.

Advancing health equity: Good alignment. The study will characterise prescribing and outcomes across demographic and geographic groups, which may support more equitable implementation of pharmacogenomics in the future. Care must be taken to ensure that these breakthroughs are applied in ways which advance health equity, as they will necessarily have a non-neutral effect. The description of the focus in Genomics, Healthcare and You is laudable and offers a plausible mechanism by which policy can be influenced appropriately, through active engagement with underrepresented communities, in line with Genomics England's Diverse Data vision.

Alignment to the Legal Directions

We note that the authors have determined that this project does not meet the HRA definition of research requiring HRA ethics approval at this stage, which is in line with PAG's understanding that the researchers are not accessing identifiable data.

PAG identifies that the project type description of "Data gathering to inform study design" aligns with the intended purpose of research, which means that the project can take place within the legal direction for OpenSAFELY.

PAG understands that despite this, the Sponsor retains overall responsibility for the end-to-end ethics of the overall research, and the Sponsor must be satisfied at all times that the component work satisfies ethical considerations.

GP Data

While many pharmacogenomic medicines are commonly prescribed and therefore readily observable in GP records (for example PPIs, antidepressants, clopidogrel and warfarin), a subset are initiated or managed through specialist pathways, including HIV services, neurology services and mental health trusts. The authors may wish to consider whether prescribing visibility differs between drug classes and whether prescribing sourced from specialist services is consistently represented within the datasets used for study design.

For some of the drug treatments in the CPIC and CERSIPGx guidelines, the only presence of the drugs in GP data may be as the recording of an external prescription issue undertaken manually, in line with good practice for drugs which may be important for prescribing decision support purposes, and to render the presence of drug treatment into local, regional and national shared care records. This could include the use of specialist treatment for ADHD issued through a community mental health trust, which may or may not be recorded in the GP record.

The authors describe the presence of associated outcomes that they intend to collect, which PAG infers to be typical end-outcomes such as blood pressure control and end-organ damage for those having antihypertensive treatment, and upper GI bleeding for antisecretory treatment. PAG is willing to comment on the presence or absence of data quality issues when using GP data for outcomes, if a specification is offered.

PAG encourages the authors to read the guidance produced on the selection of appropriate code lists, and cautions against automatically using the GP Quality & Outcomes Framework code lists without scrutiny, because of their differing use-case to the broader research questions GEL is considering.

National Data Opt Out

PAG notes that this study does not match genomics data with existing health datasets, and notes that the authors have not chosen to apply the NDOO, which is in line with the policy approach within OpenSAFELY which is that it is not required.

Publication of findings

The use of OpenSAFELY to inform future study design is materially important to understanding how the Service can perform for such a use-case, and PAG therefore encourages the authors to publish relevant findings of the OpenSAFELY project (for example, a summary of the data gathering to inform study design and how that influenced the next stage of the research plans) in addition to the intended onwards use, so that benefits and challenges of using this approach are documented for the benefit of the wider community, and the teams working with the system to understand the true scope and potential for the platform.

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Application Details		
NIC Reference:	DARS-NIC-812486-T0C2N-v0 OpenSAFELY Ref: AOS-2026-1067	
Application version Number:	V0	
Applicant Organisation:	Imperial College London	
Application Title:	Pancreatic cancer-related healthcare	
Attendees		
Representing Organisation	Name	Role
British Medical Association (BMA)		BMA Representative
Royal College of General Practitioners (RCGP)		RCGP Representative
Declarations of Interest		
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☐ Clinical audit ☒ Service evaluation ☐ Health surveillance ☐ Research ☐ Evaluation of the service ☐ Health & social care policy, planning & commissioning & public health
1c. Advice from the Profession
Approved
Supporting statement:

Strategic alignment with the profession

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

Population health and care: Strong alignment. Pancreatic cancer remains one of the most lethal cancers, and the study is focused on understanding opportunities for earlier diagnosis, more timely investigation and improved outcomes. The work aligns closely with prevention, early detection and population-level improvement in cancer services.

Patient experience: Strong alignment. Delays in diagnosis, access to investigation and progression through the cancer pathway are central themes of the project. The study directly examines issues which are highly consequential to patients and their families, as well as the complicated issues that can arise during its treatment, when blood glucose metabolism is affected.

Effective use of resource: Strong alignment. The project evaluates both a national case-finding programme and the quality of data used to support diagnostic pathways. It has direct relevance to commissioning, service planning, digital transformation and allocation of diagnostic capacity.

Advancing health equity: Good alignment. The study proposes comparison across geography, healthcare provider settings, ICBs and patient groups, providing opportunities to identify variation and inequalities in access to investigation, diagnosis and outcomes.

Staff experience: This does not seem to be in scope for the study, and any benefits to staff may be indirect, through increased confidence in case finding, as opposed to the experience of providing care.

GP Data

This project offers a valuable opportunity to assess the impact of a study which is taking a simultaneous approach to the critical appraisal of data quality, as well as the measured effects of its own data quality improvement work. This is a fundamentally interesting approach in primary care informatics, and has the support of the Joint GP IT Committee, who continue to advocate for a national data quality improvement programme.

We note that in some areas, coding will be relatively complete, and not in others. For example, the coding of abdominal symptoms is inherently individual in terms of each clinical user, and 'what gets coded' has already passed through a significant filter of the clinical mind.

PAG notes that imaging results in primary care are often received as free-text associated with a (procedure) code, and therefore the data may reliably record the presence of a referral but the absence of a code does not reflect the absence of an imaging referral. This is in part because where requests for radiology are processed through ordercomms clinical systems, those requests may be structured within the third-party ordering solution, but the tests requested do not result in coded items within the primary care record. For example, a CT abdomen may be ordered using an ordercomms solution, but only the result will be accessible in the coded record. In considering the fitness of GP records for research, policy recommendations may naturally arise that these ordercomms solutions should be encouraged to record the data in a way which is accessible for care outside the source record i.e. shared care record systems, and for research, by adaptations to ensure the requests are coded in SNOMED-CT.

PAG also notes that referral for further investigation can be difficult to establish from GP data, noting that in addition to the limitations of ordercomms systems, regional variations in commissioning of direct-access testing may be associated with less technically mature systems of record, such that traditional coding of GP->Hospital referral or requesting may only be recorded in document format, and not necessarily as structured data. The contemporaneous drive towards using Advice & Guidance via the NHS e-Referral Service may also create gaps in the data, where a request cannot be differentiated as being a request for further investigation, a request for further advice, or both.

SNOMED-CT specification

A brief review of <https://digital.nhs.uk/binaries/content/assets/website-assets/corporate-information/directions-and-data-provision-notices/data-provision-notices/cancer-programme-pilots-evaluation/pancreatic-case-finding-technical-output-specification-.xlsx> was undertaken, and the authors have confirmed that it is current. The document refers to uploads of Pilot patient-level dataset (V0.6).

The document is a coding specification in isolation, without the surrounding information model which would help understand how the codes are to be used. The coding model makes sensible choices about which data are likely to be found in GP records. There are a series of difficulties which the authors will encounter in comparing the study practices with comparator practices, because the coding model appears to be bespoke to the study, and includes the use of some SNOMED concepts which are not conformant to SNOMED UK policy such as 373808002 | Curative - procedure intent (qualifier value) | which is a component of SNOMED designed to be used in post-coordination, not in data entry. PAG also notes that the data may be vulnerable to contamination e.g. where 183833005 | Referral for computed tomography (procedure) | is used to identify the act of referring the patient to have a CT (which includes the pancreas) in response to the Pilot study. Without post-coordination (such as combining the presence of this code with other codes appearing in the same Encounter / Consultation, this risks the misattribution of CT

requests done for other reasons or other body parts undermining the validity of the extracted data.

The authors have confirmed they are aware of these issues.

These are problems inherent within the current implementation of SNOMED-CT in the UK which remains heavily dependent on the use of pre-coordinated concepts, and is not specific to this study (but is specifically applicable), when trying to extract data which sequence specific clinical pathways where the only concepts available may be used for other reasons e.g. 32962002 | Computed tomography of abdomen with contrast (procedure) | may be a CT scan result that is unrelated to the imaging of the person's pancreas that was requested as part of the cancer programme.

In publication, these constraints are worth highlighting, and the authors may wish to comment on whether GP supplier systems should be encouraged to enable systems which allow the coordination of linkage of items, for example by the coordination of system artifacts (data entry templates, data entry protocols) which would enable higher data quality analysis in pilots such as this, even in the absence of implementing full SNOMED post-coordination.

Identifying organisations down to practice level

Rationale

PAG acknowledges the goal and intention to analyse to practice level, and the rationale for doing so, which is stated as being to evaluate the impact of the intervention in the selected practices, who opted in to this work, and comparison with practices who did not.

PAG thanks the authors for confirming that the publication is intended to be of data aggregated thematically, and not by individual practice or PCN.

The challenges in data quality noted above illustrate some of the reasons why significant caution is required in comparative analysis, and why the profession is keen to ensure that this is considered on a case-by-case basis.

Policy considerations

PAG reviewed its existing paper “Ensuring validity in interpretation of organisational level data from general practice” which sets out PAG’s role and mandate in reviewing requests to analyse down to practice level, and is relevant to the project goal.

The relevant existing governance steps are:

1. requests to identify to PCN or practice level must be approved by PAG
2. data output checks on OpenSAFELY data are made available to authors are reviewed prior to release. The data are checked to ensure that PCN/practice level data have not been identified without authorisation.
3. the DATAPAST service will check for identification of PCN/practice level data, which may have been generated

PAG would not support publication of practice-level identification of the practices outside the study practice cohort. Non-cohort practices' data can sensibly be grouped in a variety of different ways such as by ICB, or by other criteria that enable comparison such as approximate list sizes, etc.

The OpenSAFELY Data Analytics Service Pilot does not currently allow bring-your-own-data by policy, and technical work would be required in order to enable the list of selected practices to be brought into the platform in order to suitably label the data belonging to those practices.

This leaves two initial options, with our preference being for the second option (B):

A. Data compared outside OpenSAFELY

PAG exercises its authority to allow the sharing of practice level data for all practices (which would require adaptation of OpenSAFELY). Data output checkers would be authorised to allow the release of those data, and PAG would then rely on DATAPAST to consider the final publication for suitability. PAG would require assurance that the underlying mapping would not be exposed more widely in the process.

B. Data compared inside OpenSAFELY

We would wish to consider how OpenSAFELY might adapt in order to allow data processing to be undertaken within the platform in order to support the end outcome.

- a. PAG would support discussions of a specific policy exception for this study, to consider how the importation of a list of practices could be undertaken in such a way as to facilitate a comparative analysis within OpenSAFELY
- b. This study is a good candidate on which to base such discussions because of its strategic value, the integration of prospective data quality improvement work, the collaborative approach taken to practice engagement, and potential demonstration of OpenSAFELY as a mechanism for work which would otherwise have required legal directives in order to be accomplished.
- c. If it can be demonstrated that comparative analysis can be performed within OpenSAFELY, then that would be valuable to strategic decision making for OpenSAFELY.

Having understood from the authors that they would prefer to work within OpenSAFELY, PAG will set out to the OpenSAFELY team what the requirements are from the profession, to support discussions on what work would be necessary to enable the study to proceed.

To what extent are the study practices aware that they will be identified?

The authors have confirmed that the precise publication intentions have not yet been specified, and there is no specific agreement with the study practices.

PAG understands that the processing of the data relating to the study is already be taking place as described under the Cancer Programme Pilots Evaluation Directions 2024 <https://digital.nhs.uk/about-nhs-digital/corporate-information-and-documents/directions-and-data-provision-notice/secretary-of-state->

directions/cancer-programme-pilots-evaluation-directions-2024 with practice-based collection of data, including the coded and uncoded data in the specification.

PAG considered what it would have required if the authors wished to identify the study practices, and concluded that we would want to know

- what opportunity practices had to understand that their data would be published at practice level
- what consent if any was sought implicitly or explicitly, whether this was standardised across all practices, and whether records are available should a practice wish to confirm their consent to being identified.

PAG would have sought to establish that all practices participating in this study had the reasonable expectation that their care would be identified in this way.

National Data Opt Out

The NDOO does not need to be applied under OpenSAFELY policy unless there are specific reasons to do so, and this appears to represent an advantage for the power of the study, because the NDOO is applied under the Requirements Specification for the existing data processing.