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AMA feedback on the draft National Primary Health Care Data Collection (NPHCDC) Data Governance Framework and draft Terms of Reference

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Executive Summary

The AMA welcomes the National Primary Health Care Data Collection (NPHCDC) and has long called for better general practice data collection and research to address the data gap left by the funding cessation of the Bettering the Evaluation and Care of Health (BEACH) dataset in 2016. The AMA's Position Statement on Data Governance and Patient Privacy 2023 states that data governance must be patient-centred and based on safety, quality, privacy and portability, with clear legal, technical and ethical safeguards to maintain trust and support quality improvements and health system planning.

The NPHCDC must inform and support evidence-based health system design and planning, have robust governance that prevents harm, protects privacy, prohibits commercial exploitation, and deliver practical value back to general practice. The draft Framework has a strong foundation, including the NPHCDC use of de-identified unit-record data, secure environments, and limiting public release to aggregated outputs that have undergone confidentialisation. However, general practitioner (GP) trust in the NPHCDC will depend on clearer, enforceable guardrails — particularly around protection against commercial access and monetisation, transparency, audit assurance, and a meaningful value proposition.

The AMA calls for the Framework and Terms of Reference to:

1. *Strengthen safeguards that build GP trust*
   In plain language, the NPHCDC must ensure and communicate that it contains no identifying patient information and reinforce that the data will not be on-sold or used for commercial purposes, including pharmaceutical or device companies.
2. *Clarify "public benefit" and tighten approval/accountability mechanisms*
   The term "public benefit" requires clarification through defining what that entails. The Framework must also specify who is an appropriate organisation for granting ethics approval and establish an explicit audit/assurance pathway for data privacy and safe handling.
3. *Deliver value for general practice*
   The Framework should ensure the NPHCDC provides outputs that identify priority health

conditions affecting patients' quality of life, local service gaps and workforce shortfalls, and support effective action through accessible and practical feedback loops to practices.

4. *Commit to transparent reporting and ongoing trust maintenance*
   The AMA recommends publishing an annual public summary of appropriate data points and outputs, alongside reporting back to practices and Primary Health Networks (PHNs), with plain language on what is meant by the NPHCDC's "contribution to system performance".
5. *Include the AMA as an Advisory Group member*
   The AMA is uniquely situated to provide a comprehensive overview of the clinical intersections of patient care in Australia's primary care system. The AMA recommends it be included on the Advisory Group to ensure clinical relevance, implementation realism and ongoing trust with the broader medical profession.

The AMA has structured its feedback on the following themes.

Additional safeguards that would build GP trust

The draft Framework includes important protections, including prohibitions on benchmarking, auditing and investigating practices. It also prohibits tracking individual patients, and unit-record access by private/commercial entities. The AMA recommends the current prohibition on private/commercial access to unit-record data be elevated into a plain English "red line" statement that explicitly states there will be no on-selling, no licensing for commercial gain, and no sharing with marketing or pharmaceutical companies (including any pathway that enables targeting or segmentation).

If requests arise in future to use the dataset for additional research purposes, GPs who have provided practice data should be asked whether their dataset can be included. The draft Terms of Reference (ToR) notes the Australian Institute of Health and Welfare (AIHW) will rely on existing consent pathways and data sharing agreements. The AMA recommends adding a commitment that any material expansion in use case or risk profile requires an explicit re-permission step via the relevant data supply pathway (or a functionally equivalent mechanism).

The draft ToR also states the Governance Committee will *"ensure that data use supports public benefit"*. The AMA recommends defining "public benefit" — in plain language — for greater clarity and include a requirement to publish and make publicly available the decision test used to assess projects. This should include how clinical relevance, equity, and potential harms were weighed to reduce perceived scope creep and the risk of politicisation.

To strengthen assurances and transparency, is it important to ask: "Who will audit the privacy and safe data handling?" The AMA recommends it be specified: (1) who undertakes the independent audit, (2) the timeframe (at least annually and after material changes), and (3) how outcomes will be reported. This is consistent with the Framework's stated reliance on secure settings and ethical oversight and will help give GPs assurance on the AIHW's "visible controls".

The value proposition for GPs

The Framework's population health purpose aligns with priority needs to: (1) identify diseases and conditions that may warrant more systematic screening or proactive enquiry, (2) identify specific areas of need in rural and remote settings pertaining to service gaps, specialist access pressures, workforce shortfalls, and allied health needs, and (3) ensure data outputs are clinically meaningful and support early signals for local action, not just retrospective reporting. This will enable PHNs and governments to better deliver practical and targeted responses to support GP-led multidisciplinary care.

The AMA strongly suggests better clarification to de-jargonise *“contribution to system performance”*. As drafted, it reads as administrative doublespeak. A plain English description should explain the purpose of NPHCDC’s data output in practical terms. For example, how does primary care activity and access data inform population health outcomes and health system planning. At the same time, it should reinforce that outputs are aggregated and contextualised.

Governance red flags that need addressing

The AMA agrees the draft ToR is directionally strong but recommends addressing several implementation risks to protect trust and data quality. It is critical to protect against, as one member put it, *“tokenistic and top-down levers applied to… busy private businesses”*. The Framework’s “no additional burden” principle is crucial and the NPHCDC’s operations should be tested against this regularly. The AMA recommends strengthening this principle by explicitly stating that data quality uplift and standardisation will be supported through automation, tools and resourcing rather than shifting coding workload onto clinicians without appropriate administrative support and financial remuneration.

Members have highlighted the risk that general practice will be viewed through a reductionist lens if classification choices are hospital derived and poorly fitted to primary care. The AMA recommends treating coding/classification as a priority governance workstream, with explicit primary care input and transparent decision-making, as this directly affects the clinical meaning and usefulness of data outputs.

There is also a need for clearer language where re-identification risk is referenced. The AMA recommends tighter and straightforward wording, so it reads consistently to a GP audience and clearly explains how risk is managed across the lifecycle of the NPHCDC (inputs, secure settings, and outputs).

AMA representation on the Advisory Group

The AMA seeks representation on the Advisory Group and notes its long-term relationship with the AIHW. The AMA supports the AIHW as best placed to collect the data, provided governance remains strong and focused on better health outcomes and service delivery. The AMA’s participation will ensure clinical relevance, appropriate interpretation of outputs, effective implementation (including the operational realities of general practice), data outputs are designed for actionable improvements, and that trust with the medical professional remains high.

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