Australian College of Nursing

AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE CONSULTATION ON NATIONAL PRIMARY HEALTH CARE DATA ASSET

A Submission by the Australian College of Nursing (ACN)

Survey Questions

Section 1

1. **What is your email address?**

   policy@acn.edu.au

2. **Who are you providing a submission on behalf of? (Select)**
   a. **Individual**
   b. **Organisation**

3. **If submitting on behalf of an organisation, which one? (Name of organisation – required)**

   Please write 'not applicable' if submitting as an individual
   Australian College of Nursing

4. **Do you consent to the publication of your organisational name? (select)**
   a. **Yes, I do consent to the identification of my organisation.**
   b. **No, I do not consent to the identification of my organisation.**
   c. **Not applicable.**

5. **Which stakeholder group best describes your affiliation? (select one)**
   a. **Consumer**
   b. **Provider of primary health care services**
   c. **Commissioner of primary health care services**
   d. **Policy maker**
   e. **Researcher**
   f. **Provider of clinical information system/infrastructure**

Section 2: Introduction

The following five questions apply to the development of the National Primary Health Care Data Asset, its uses, priorities, barriers and enablers.

1. **What do you see as the key areas of opportunity in developing the National Primary Health Care Data Asset?**

   - Data on services targeted to specific population sub-groups. For instance, earlier recognition of chronic disease in Aboriginal and Torres Strait Islander (ATSI) populations leading to a greater opportunity to prevent or put chronic disease in remission or regression. Understanding the type of action taken (MBS Item) would help in assessing the quality of care given.
     ATSI people access Primary Health Care (PHC) through both private general practice and primary health services specifically designed to meet the needs of ATSI peoples, including Aboriginal community controlled health services (ACCHS), and government operated Indigenous-specific services. It should be a priority to collect this data as ATSI people face significant barriers in accessing PHC and particularly due to concerns for early recognition of possible cardiovascular diseases in ATSI people.

   - Recognition of Nurses' work, particularly Nurse Practitioners (NPs). There is an increasing number of NPs in PHC and their contribution needs to be recognised to establish their achievements, and to assess and make use of the true scope of their practice. Because NPs are generally underestimated and not recognised for their work, there is a pool of underutilised skill that is being wasted. Data and analysis will make a significant difference in the area. NPs can make positive contributions, particularly in remote and regional areas, by understanding the level of care and possible gaps. This is an opportunity to promote the profession of nursing as the most trustworthy and their capability to lead PHC implementation in Australia across the healthcare system. This will allow PHC to benefit from the holistic role and leadership of nurses in multi-discipline teams.

   - Ability to have a national picture of PHC allowing an assessment of gaps, needs and potential within the system. It could be an Australia-wide, cross-discipline data set to guide and support practice. It will help to identify inequalities in access, noting increasing demand and changing health environment, to assess how these needs can be met and inequalities can be reduced. However, it is important that this data set is not focused solely on doctors in General Practice (GP). It must have the ability to consolidate data capture across a range of GP, state and community health, as well as other PHC providers. It is an excellent opportunity to invest in other areas of PHC, to ensure that the data asset reflects actual work across all spectrums and not just those in GP.

     Projected population planning, with an identification of patient journeys through the health system by type of patients. Specifically, it will allow better planning of care pathways for people with more complex health issues and data to establish better community hubs with multidisciplinary teams to undertake care. For instance, young people with intellectual disabilities or Autism.

   - Examination of return on investment for government and help with decisions about funding - are we putting our money in the right places, is it actually having any benefit and how efficiently are we operating - why are there limitations in access and quality?

- Collection of data to inform the future is highly important. Without documentation or data collection, there is no proof of something having occurred, and we have no ability to truly learn from our mistakes.

2. What are your top primary health care data needs?

- Data on Nurse (and Nurse Practitioner) interaction with, and input and contribution to the patient journey. Nurses also have an important informal role in communities that should be recognised and taken into account. This includes activities such as frontline education to patients and their families, assisting people to improve their health care habits, chronic disease care - the effect nurses have is amplified by the health benefits to patients and families.

- ACN released a position statement in 2015 titled, *Community and Primary Health Care Nursing*, calling for full recognition of the role of nurses in PHC and their ability to practice to the full capacity of their scope and contribute to PHC. "Australian College of nursing (ACN) considers the roles of community and primary health care (C&PHC) nurses to be integral to ensuring optimal health outcomes for all people across their lifespan. Community and primary health care nursing (C&PHCN) applies a social model of health care that addresses the health needs of individuals and communities while considering the social, economic and environmental factors impacting their health. C&PHC nurses are employed as generalists and/or specialists. They work across all geographical areas in Australia and in a wide range of service delivery settings. These settings include community health centres, women's health services, general practices, schools, prisons and peoples' homes and work places." (ACN, 2015)

- Child and family health, particularly antenatal care - this is where primary health and wellness begins, prior to development of chronic disease.

- Mental health, indigenous health, suicide prevention, demographic information, projected population change, burden of disease by population, vulnerable communities' health information, and potentially preventable hospitalisation data.

- Data on Quality of Aboriginal Health Checks being undertaken. Currently no chronic disease evaluation needs to be undertaken for this (MBS) item to be claimed

- Home visiting nurses data, and some health databases such as Victorian Integrated Non-admitted health (VINAH), Commonwealth Home Support Program (CHSP) etc.

- This data development plan is primarily focused on general practice (GP), limited only to the work of general practitioners initially. Whilst, GP is a vital component of PHC, PHC is much greater than the medical model of healthcare. The approach of the Development plan discussion paper excludes an enormous amount of work being undertaken by other health professions and within other settings, particularly work by nurses, who work in general practice and across numerous PHC sites and models of care. ACN argues that this data is equally (if not more) important in our current health environment because of the significant interaction and relationship nurses have with their patients and the important role they play throughout a patient's journey, spending a large amount of time with them, understanding their needs. Furthermore, nurses are at the forefront of delivery of care, particularly in areas that have limited access to care, as well as areas of sensitivity that are

significant to care, including prevention of chronic diseases, Alcohol and Drug education provision, immunisation, as well as support and guidance to women, parents, and children to start and maintain a healthy life etc. Not recognising these vital roles nurses play and not collecting data from these specific areas, makes it impossible for us to support and enhance these services that are important for a sustainable PHC system and its goals.

3. **Please rank in order of importance the following topics from the Data Development Plan (1 being the most important and 6 the least - Drop down boxes: with rating of 1 to 6).**

    a. **Data Sources 1**

    b. **Data Governance 4**

    c. **Data flow models 6**

    d. **Data element selection 3**

    e. **Data indicators 2**

    f. **Reporting Requirements 5**

4. **From your perspective what are the top three barriers and their enablers in developing the National Primary Health Care Data Asset?**

    a. **Barrier #1: _____**

    b. **Enabler #1: _____**

    c. **Barrier #2: _____**

    d. **Enabler #2: _____**

    e. **Barrier #3: _____**

    f. **Enabler #3: _____**

1. Barrier: Narrow 'medical model' approach and limited data sources: Exclusion of some important areas and professions within PHC, such as community health care (which is expected to be included in the longer term: 7-10 years), as well as dominance of the current PHC medical model which has a selective focus and ignores the role of nurses and needs of patients. Further, in rural and remote areas there are strong nursing PHC models which do not fit to the medical model. There is a focus on city area needs and practices relative to rural and remote area practices and patient needs. This is exacerbated by the current limitations in data sources - if this data asset will only collate and provide from existing data sources, then it will as a result overlook the most vulnerable and underestimated areas and roles in the patient's journey in PHC. A complete and true picture requires new data sources and a broader scope.

   Enabler: Ensuring broader stakeholder engagement (particularly nurses who are a major component of PHC), as well as a broader scope for PHC. A change in perspective on what is important and requires more attention for effective PHC needs to take place. A regional- and

community-based approach to PHC that is patient-centered must be undertaken to enable the data asset to yield useful data.

2. Barrier: Understanding patient needs: There is no available mapping of what services are actually provided and what services are needed. The proposed limited data set will be used to reflect what services are being delivered, and may as a result be used to make decisions about what patients need. Instead of filling gaps (due to a focus on GP in the first instance), this data will be missing out on many areas where demand is not being met and access is limited, particularly for regional and remote areas. The proposed data will not specifically look at the role of nurses (even in the long term), while nurses are the ones who have the most interaction with patients and will be able to contribute to truly understanding patient needs.

   Enabler: The Data Asset needs to account for nurses, community and other informal types of care; a focus on GP and then on Allied Health Professionals disregards a major component of PHC. Data also particularly needs to be gathered for gaps in services or in unmet patient needs. There needs to be in-depth research into what we are measuring and what these indicators actually mean.

3. Barrier: Information sharing and Interoperability: data systems not talking to each other and current funding model with reporting focused on outputs.

   Enabler: Ensure communication and compatibility between sources of data - collection and use of data are equally important. There needs to be an agreed national data ecosystem or framework and a mandatory set of technical compliance standards. Support needs to be given to software providers to increase harmony (i.e. so that data systems talk to each other and data makes sense) between them and maintain standards of high quality useful data. The advisory group that is planned to assist in implementation and use of data at later stages should be inclusive of all stakeholders in PHC.

5. In order of priority, rank the following uses of the National Primary Health Care Data Asset (1 being the top priority and 7 the lowest priority).

- **a. Support quality improvement 6**
- **b. Enable better population health planning 7**
- **c. Help identify gaps in the provision of primary health care services 4**
- **d. Shape primary health care programs and policies 3**
- **e. Provide the best evidence to be able to reduce hospitalisations and emergency department attendance 5**
- **f. Facilitate increased efficiencies in care delivery through comparison of patient outcomes and services across geographic and socioeconomic gradients 2**
- **g. Improve patient outcomes and experiences 1**

Section 3: Data Sources

(Attached National Primary Health Care Data Asset Plan)

Section 3 of the Data Development Plan outlines existing and new primary health care data sources and how they will inform the Data Asset. We are particularly interested in your views of our proposed new data sources and the phased approach to their implementation, what you see as the pros and cons of the potential models of data flow (Figure 3.2) and if there is anything additional we should consider in the decision making process when assessing data sources for inclusion (Figure 3.3).

1. **Which is your preferred model of data flow from general practice to the Data Asset (Figure 3.2)? (Select one and then comment)**

    A. **General practice direct to Data Asset**

    B. **General practice to Primary Health Network to Data Asset**

    C. **General practice to Clinical Information System to Data Asset**

    D. **General practice to Data Collator to Data Asset**

    E. **General practice to Primary Health Network to State and Territory Health Department to Data Asset**

    F. **Other**

    G. **Comments:** there are certain concerns about Primary Health Networks (PHNs) not having complete mapping or a full picture of the GPs and or services in those PHNs, as well as issues of compatibility, privacy and efficiency that need to be considered and solved before going forward. The Data Development Plan should account for this when finalising a data flow model.

2. **What are the implications, opportunities and challenges for the proposed general practice data flow models (Figure 3.2)?**

    The Data Asset is planned to only build upon and take advantage of existing data sources. However, to truly gain an understanding of a patient's journey, the Data Asset must also discover new sources for collecting data and fill gaps in data. Currently, there is limited PHC data and to rely alone on existing sources of collected data would be to proliferate current gaps - true patient needs and priorities will not be identified. If the Data Asset is to successfully provide a national PHC data set that will reduce inequalities in access and support an effective and integrated care approach, it must capture all areas of PHC, particularly the most vulnerable (where least amount of data collection occurs).

3. **What potential data flow models could capture other primary health care data sources: allied health, community, dental?**

    Current suggested data flow models are only considering General Practice (GP) electronic health records as a data source. Future suggested data plan includes allied health data (in 5 years time) and community and dental health data (in 7-10 years time).

    ACN believes these timelines are not realistically covering PHC priorities by level of importance and need. Nurse data has not even been mentioned as a data source in the development plan at this stage or in the long run. To have a useful and effective Data Asset, it needs to give us what we don't already

have and what we really need to make informed policy decisions about patient needs and how to meet them.

In the first instance, research and analysis work needs to be undertaken to find ways of collecting data from all areas of PHC - instead of all focus being on GP, a few data measures from all areas need to be identified and data needs to be collected for them. This narrow approach to PHC with a sole focus on doctors in GP will not give a real picture of PHC and it not provide us access to useful new data. Based on current and ACN suggests data sources, below is a proposed data flow model.

Suggested data flow model:

Data Sources:	**Medium:**	**Output:**
Community and informal care (Nurse Data) General Practice (not just doctors) Allied Health Dental	Data collator/ Data Framework and standards	National Primary Health Care Data Asset

4. Are there additional sources of primary health care data you would like to see included?

- Signs and symptoms. Nurses, having the most interaction with patients, generally are most well-placed to make observations and engage in communication. There is an opportunity in capturing data from nurses when conducting opportunistic preventative health discussions and care coordination particularly when they have longer interaction with patients e.g. wound dressing, vaccines, health assessments etc. Further, data can be captured through:
    - Health checks in the 45-49 age health group who are at risks of Chronic disease.
    - Ages 40-49 Diabetes risk assessment tool (AUSDRISK)
    - Opportunistic preventative health discussions when doing vaccines or dressings, such as when a nurse doing a flu vaccine or dressing may have a client who is over 70 and advise they are entitled to a free catch up vaccination for Shingles (herpes zoster) until Oct 2021
    - Coordinated Veteran Care (CVC) Program which has been very successful in improving health outcomes in Veterans, where nurses have an important role to play.

- All areas of nursing such as health assessments undertaken by NPs, as well as health promotion, education and responding to needs related to chronic and complex diseases by nurses. The main issue with the draft Data Development Plan is not that it is only temporarily focusing on doctors in GP, it is that the plan considers everything besides general practice to be relatively unimportant. There is a lack of awareness about how important the role of nurses in PHC is, because of which the plan's 10-year milestones do not even include nursing as a small part.

- Particular areas: Maternal and child health, social and family support network. Child and family health nurses facilitate improved health and social outcomes for children and their families through promoting child and family health and educating parents on child development. A key focus of their role is the monitoring of child development, early detection of developmental delays or health conditions, and the coordination of early interventions. They also monitor for signs of family distress caused by postnatal depression or domestic violence and undertake steps to institute what treatment or help may be required and to protect vulnerable individuals.

- Mental health and disability profiles.

- Data from school based clinics. School health nurses and school health nursing programs are a direct and major provider of PHC to children, students and their families in the school context. School health nurses also provide a collaborative PHC resource to school staff, such as teachers. Data related to the provision of PHC to children and their families within the school community should be collected. This can include at a minimum developmental and health screening, health promotion activities, and increasing health literacy.

5. **How satisfied are you with the decision making matrix for assessment of new data sources?**
    a. **Highly Satisfied**
    b. **Satisfied**
    c. **Somewhat Satisfied**
    d. **Dissatisfied**
    e. **Strongly Dissatisfied**
    f. **Comments:** The matrix limits many important areas that could be very useful if considered, by making them 'infeasible'. Many data sources that would help increase feasibility of other data sources (such as nursing data input) that should be included are not included in the plan. It seems that more data sources will not pass the matrix 'test' than sources that will. This will not allow a true, holistic picture of a patient's journey in PHC. Nurses and other health professionals, as well as community care, and other areas of PHC besides GP need to be given their due importance.

6. **Do you have any additional comments or suggestions regarding data sources?**

    The consumer/patient needs to be considered first and foremost - how can we truly capture their journey without capturing their most vulnerable interactions with all other health professionals, particularly nurses?

Section 4: Data Governance

1. **How satisfied are you with the proposed data governance arrangements?**
    a. **Highly Satisfied**
    b. **Satisfied**
    c. **Somewhat Satisfied**
    d. **Dissatisfied**
    e. **Strongly Dissatisfied**
    f. **Comments:**
2. **Do you have any additional comments or suggestions regarding data governance?**

Overall, the proposed data governance process stated in the draft Data Development Plan seems comprehensive. Particularly, 'management' and 'storage' (which is always a big concern pertaining to personal data collection) section seems to be covering relevant concerns. The Five Safes model will be a strong basis for this big responsibility.

However, it needs to be ensured that there is proper accountability in this process and all stakeholders have a say about how this data is being managed. Currently, focus is more on General Practice (GP) doctors data rather than what we need to do to increase efficiency in meeting patient needs - patients should be more involved. It is important to have an independent body to govern data in a transparent and agreed upon manner. Furthermore, the governing body will be important in making decisions about how this data will be used to improve patient outcomes - it would be more reliable to have an advisory committee consisting of all types of health practitioners in PHC (including nurses, especially NPs) and consumer (patient) representatives.

ACN released a position statement in 2015 about the role and importance of community and primary health care nurses. "The skill sets of C&PHC nurses enables them to make a large and substantive contribution to the delivery of community and primary health care through:

- combining care delivery with health promotion, illness prevention and community development;
- providing generalist frontline services, that aim to improve the health outcomes of disadvantaged individuals and communities, that are responsive to cultural needs;
- providing support and guidance to women, parents and families so children have a healthy start in life;
- case-finding people and groups requiring preventative health care such as health screening or immunisations;
- responding to health care needs arising from increased population rates of chronic and complex disease and more people reaching older age; and
- Liaison within and coordination of care across the health care system and between service providers from other sectors." (ACN, 2015)

Section 5: Outlines Information pertaining to the data requirements

1. **How much do you agree with the proposed list of core data elements suggested in Table 5.1?**
    a. **Highly Satisfied**
    b. **Satisfied**
    c. **Somewhat Satisfied**
    d. **Dissatisfied**
    e. **Strongly Dissatisfied**
    f. **Comments:** the list of core data elements seems very useful; however, the main problem is the narrow focus to only GP and doctors.

2. **How much do you agree with the potential indicators for general practice outlined in Table 5.3?**

a. **Highly Satisfied**

b. **Satisfied**

c. **Somewhat Satisfied**

d. **Dissatisfied**

e. **Strongly Dissatisfied**

f. **Comments:** again, the list of data elements seems very useful, however the main problem is the narrow focus to only GP and doctors, without inclusion of other main important areas of PHC and other health professions such as nurses.

3. **Please list any primary health care data gaps not identified in the Data Development Plan.**

   The Data gaps listed do not mention Nurse (RNs and NPs) contribution and services data. It is not even listed as a potential data source anywhere else in the plan. The plan does not recognise or mention the role and importance of nurses and their contribution to Primary Health Care. In doing so, it is made clear that there are no plans, now or in the future, to include nurses in this Data Asset. This is a huge oversight considering how important the role of nurses is to the future of an effective and sustainable PHC system.

4. **Do you have any additional comments or suggestions regarding data requirements?**

   ACN supports the possibility of looking into Patient-related experience measures (PREMs) and Patient-reported outcome measures (PROMs) data in the future. PROMs allow us to capture a person's perception of their health, validated generic and disease specific tools, as well as measurement of symptoms, distress/anxiety and unmet needs. While PREMs capture a person's perception of their experience with health care or service.

   This data is likely to provide great insights and guide the future of PHC. Reporting on patient experience allows patients to provide direct feedback on their care to drive improvement in services, enhancing care co-ordination, communication and case management.

   There are a few ways of collecting this data: surveys, focus groups, patient stories or journey, and observation. Nurses are in the best position to make observations and provide/assist in collection of data in mapping a patient's journey.

   Research shows advantages of PREMs and PROMs to include:

   - Improvement in detection of worsening symptoms,
   - Providing information that may otherwise have been missed,
   - Improvement in outcomes and reduction in dropout,
   - Ensures voice of service user (patients) is heard.

Section 6: Summary

1. **From your perspective, what else should the AIHW be considering in the development of the Data Asset**

- Inclusion of patient education and health literacy discussion/data would be beneficial.
- Recognition that the profession of nursing is are the current leader in providing PHC service, activities and interventions. In the draft Data Development Plan, nurses are grouped together with allied health professionals and yet nurses represent a much more significant proportion of the PHC workforce. They work within general practices alongside GPs rather than in private clinics such as physiotherapists and dentists. Thus grouping them with allied health in this context is neither appropriate nor accurate. Nurses face different issues and challenges that need to be recognised. Nursing should be mentioned as a separate entity and new data should be collected for nurses' independent contribution.
- No community health data is envisioned for 7-10 years (3rd tranche), which means excluding all the work of community and other nurses for the near future. Three importance areas that are significant to PHC and where nurses play a very important role are: supporting people with chronic and complex illnesses; Child and Family Health Nursing; and, PHC for marginalised populations (such as ATSI). ACN strongly believes that the demonstrated potential of Community and PHC nursing could be further maximised through policies and models of care that enable nurses, including NPs to utilise their entire scope of practice. In order to understand the true value and current underutilisation of nurses, particularly NPs, ACN strongly urges that data related to nursing in PHC be collected and analysed as a priority.
- WHO identified organising health services around people's needs and expectations as one of the key elements to achieving the PHC's ultimate goal of better health for all. ACN believes this is currently missing in the draft Data Development Plan. WHO has stated: "Primary health care is well-positioned to respond to rapid economic, technological, and demographic changes, all of which impact health and well-being. A recent analysis found that approximately half of the gains in reducing child mortality from 1990 to 2010 were due to factors outside the health sector (such as, water and sanitation, education, economic growth). A primary health care approach draws in a wide range of stakeholders to examine and change policies to address the social, economic, environmental and commercial determinants of health and well-being. Treating people and communities as key actors in the production of their own health and well-being is critical for understanding and responding to the complexities of our changing world." https://www.who.int/news-room/fact-sheets/detail/primary-health-care

2. What do you see as the biggest risks in developing a National Data Asset and how would you mitigate them?

The biggest risk as viewed by ACN is that there may be a rush to undertake this huge project of having a Data Asset that is useful for growing PHC as a sustainable system for the future. In this rush, a few of the most important areas of PHC - not just for the present and near future, but completely in the development plan. ACN urges AIHW to undertake another phase of research and analysis to make the scope of data broader. Further, nurses form more than half of the health care workforce, and ACN calls AIHW to involve nurses in the advisory and decision-making process, which has not been done at all so far.

3. Do you have any final advice or comments for the AIHW?

- Potentially, a significant amount of data will be collected. Therefore, AIHW should ensure this data is being effectively used, rather than just collected. This also includes involving all relevant stakeholders in the decision making process.
- Privacy: Information should be de-identified and kept secure.
- ACN members believe this data set has great potential and could be very useful in informing policy if PHC is considered as a whole and not just General Practice or sole focus on doctors.
- Minority groups need to be captured e.g. refugee, trauma victims, intellectual disability, mental health and complex medical issues. This would allow the health system to identify and put in reasonable adjustments to care and where extra support needs to be developed to assist primary health care to improve overall health of the population and prevent further deterioration
- Monitoring dental care is an area that at the moment is missing and this could help to develop a pathway that links dental procedures and health care together for those population groups that have issues that prevent appropriate health checks from being undertaken without the assistance of sedation.
- Nurses and their contribution should be recognised in PHC, they should not be grouped with other professions such as allied health and they should not be completely ignored or invisible in the first phase of the proposed Data Development Plan. Nurses and midwives are the largest portion of the Health workforce, particularly in PHC. Nurses spend the most time with their patients and get to know them. This, along with the fact that they are the most trusted and loved profession, also makes them powerful influencers.
- PHC services also target specific conditions and health care needs, like sexual health, drug and alcohol treatment, oral health, cardiovascular disease, asthma, diabetes, mental health, and obesity. Nurses play a vital role in this area and to not consider their role and interaction with patients would be a massive oversight.