![LUCAP - Lung Cancer Clinical Quality Data Platform logo]

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Submission to the Australian Cancer Plan 2023–2033

LUCAP is a group of consumers and clinician-researchers with an interest in improving lung cancer outcomes in Australia. Our vision is to develop a national data platform to collect and analyse clinical data from lung cancer patients in all states and territories to inform audit reports which provide comparison of clinical quality indicators (CQIs) across treatment centres (hospitals) and jurisdictions and highlight areas for improvement. The vision is ultimately to improve patient experiences and outcomes nationally.

LUCAP (Lung Cancer Clinical Quality Data Platform) is conducting a proof-of-concept, pilot study in Western Australia during 2022. It is expected this pilot will help to refine the research protocols and data infrastructure required for a national expansion of the project. Importantly, while LUCAP is focussed specifically on lung cancer, the concept is transferable and scalable to other types of cancer.

We strongly believe that a national clinical quality data platform that has the capability to make timely information accessible to health providers and patients is the key to monitoring and improving cancer services. However, at present there are barriers faced by researchers to achieving this, particularly in accessing and linking clinical data across institutions and jurisdictions. Addressing these barriers to enable the identification of unwarranted variations in care and drive meaningful clinical change forms the basis of our submission to the Australian Cancer Plan.

What LUCAP would like the Australian Cancer Plan to achieve

There are seven key areas LUCAP would like the ACP to address and achieve across the short-, mid- and long-term (noting that the latter four specifically relate to lung cancer, which is our group's primary focus):

1.   Access to Clinical Quality Data

Unwarranted variance in the quality and safety of cancer care across the country is likely a significant driver for the well documented inequities in cancer-related outcomes, particularly for:

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- Patients in regional, rural and remote areas compared to metropolitan

- Patients being treated in public compared to private health care

- Indigenous patients compared to non-Indigenous patients

- Patients living in low socio-economic areas compared to those living in higher socio-economic areas

Variation in healthcare provision has a direct impact on patients' lives. A previous study examining lung cancer survival across six countries (including Australia) concluded that differences in survival is only partly explained by stage at diagnosis, suggesting that other factors such as differences in treatment (locally or nationally) are crucial[1]. Therefore, the identification of this unwarranted variance should become a priority, together with strategies to support institutions and health services to improve care where required, and to learn from successes.

At present, there is limited flow of clinical quality data in most Australian jurisdictions and comparison of state and national performance is not possible. Australia is wasting a valuable clinical resource. The path to achieving world class cancer outcomes for all Australians will require a fundamental change in how health data is managed in Australia. At present, the process to gain access to health data is overly bureaucratic, slow, beset with multiple ethical compliance and governance barriers, with different jurisdictions having different approaches. There needs to be a cultural shift away from the protection and storage of data to the concept that patient and health service-related data should be readily available to patients and clinicians in order to evaluate and improve services. Patients deserve access to their data, and multiple reports demonstrate consumers support the sharing of data for research and improving outcomes[2,3] [4]. This will improve patient-centred care and this cultural shift will be embedded within a Learning Health System.

Efforts to establish core and cancer-specific clinical quality indicators (CQIs) should be prioritised, and patient focused outcomes highly valued. Access to these data should be as close to real time as possible and provided in a format facilitating easy identification of good and sub-optimal performance against CQIs. These data must also be provided to, and in consultation with, patients and families. Consumers deserve to know how their local institution is performing, and experience from the UK National Lung Cancer Audit demonstrates that consumers are very powerful advocates and drivers for change. When consumers know their own health history they are able to advocate appropriately.

10 year vision: A cultural shift across all jurisdictions to patients and clinicians having access to their CQI data. This will require mandatory reporting, at a federal level. Use of this CQI data to systematically and regularly audit against agreed benchmarks for standards of care for all cancers in Australia.

2.   Multidisciplinary Teams (MDTs)

There is increasing qualitative and quantitative data demonstrating the effectiveness and importance of MDTs for multiple cancer types. This translates into improved survival, better guideline adherence and more cost-effective use of health resources.

All cancer patients deserve, and should be demanding, access to a MDT. It is unacceptable that there is postcode variation with such access. Consumers need to know this is available to them and the importance of the MDT.

A change of culture within health services is required – this could be driven by strong leadership from Cancer Australia and other national bodies sending a simple message to consumers and clinicians alike: *every case of possible and/or confirmed cancer should be discussed at a suitable MDT.*

MDTs should meet minimum standards for staffing and receive regular audit against CQIs, peer review and quality assurance. The recent paper by Brims *et al.* demonstrates this is not occurring in the majority of lung cancer MDTs in Australia, and further that 1:20 institutions treating lung cancer do not even run a MDT[5].

10 year vision: A cultural shift that supports every patient with possible or confirmed cancer in Australia to have their case discussed at an accredited MDT that demonstrably meets minimum CQI standards.

3.   Smoking cessation

There is overwhelming data demonstrating the importance of smoking cessation at all stages of a cancer journey, for almost all cancers. This is across the spectrum of outcomes, from prevention to reduced complications and increased success of surgery and systemic therapies. At present in Australia there is limited co-ordinated 'on the ground' support for smoking cessation (for instance dedicated clinics or nurses within hospitals or even primary care). A nationally funded and supported smoking cessation program would provide multiple benefits and arguably be highly cost efficient. Targeted populations should include vulnerable communities including Indigenous Australians, people with mental health conditions and the homeless.

Tobacco control aligns with multiple initiatives including the National Preventative Health Strategy and National Tobacco Strategy and should:

1. Provide national leadership in cancer prevention and align with and reinforce the National Preventive Health Strategy to reduce overall cancer incidence,

2. Build the cancer literacy of all Australians, to improve understanding of personal cancer risk factors (i.e. not just lung cancer),

3. Accelerate implementation of evidence-based, best practice care,

4. Plan future workforce capacity and capability requirements by identifying national trends, addressing current and future skills shortages.

Tobacco control should be strongly aligned with e-cigarette and vaping control.

4.   Lung cancer screening

The potential for early diagnosis through a national lung cancer screening program is the most meaningful way to impact on lung cancer survival with an estimated >12,000 lives saved over ten years. Such a program will need to be linked to mature health outcome data to accurately demonstrate impact, for instance with immediate change in stage shift, long term data on

different surgical techniques, stereotactic radiotherapy, etc.. LUCAP is very strongly supportive of the feasibility work being undertaken by Cancer Australia regarding a national lung cancer screening program. Such a program will have the capacity to transform outcomes for people at high risk, but evidence of real-world effectiveness (e.g. a stage shift) will be required. LUCAP could provide this vital downstream data infrastructure.

5.   Reduce stigma for lung cancer patients

Clear public messages for continued advocacy to reduce stigma, nihilism and bias against patients with lung cancer. Lung cancer is no longer solely a 'smoker's disease'; 1 in 3 women and 1 in 10 men have no history of tobacco smoking[6].

Improved health literacy for all Australians, with improved understanding of (lung) cancer risk factors is an important health advocacy message.

6.   Funding disparity

The burden of disease for lung cancer should be reflected in a greater allocation of research funding. As Cancer Australia have presented, the burden of lung cancer, with the greatest number of life years lost of all cancers, is disproportionately funded in comparison with other cancers. At present it is inversely proportional, with just 2% of all research funding from Medical Research Council (NHMRC), Australian Research Council (ARC) and the Medical Research Future Fund (MRFF) between 2008 and 2017. This is an unacceptable and indefensible situation and the LUCAP team strongly advocates for greater resources to be dedicated to lung cancer through the Australia Cancer Plan. Furthermore, we note the decades-long under-investment in cancer control, survivorship and outcomes research representing only 6% of funding and only 1% in Scientific Model Systems[7]. LUCAP recognises the National Cancer Plan as an excellent opportunity to invest in infrastructure that will directly impact on better patient outcomes.

Our recent Commentary article highlighted that lung cancer is a major area of unmet need in Australia, and in the surrounding region[8]. Australian and US data demonstrate there is an inversely proportional relationship to lung cancer disease burden and research funding, in contrast to breast, prostate and colon cancer[7,9].

7.   Lung cancer nurses and Thoracic Surgery specialists

There should be dedicated lung cancer nurses for every specialist centre treating lung cancer. Thoracic surgery must be represented at every lung cancer MDT. At present there are so few specialist nurses, that it is not recognised as a career pathway.

Brims *et al.* demonstrate profoundly inadequate staffing across the country with 23% of lung cancer treating centres having no thoracic surgery representation, 53% no specialist lung cancer nurse and 6% no regular multidisciplinary team (MDT) meetings *at all*[5]. The inadequacy of hospital resources for diagnosing and treating lung cancer directly correlates with 1-year survival[10].

Harnessing opportunities to realise our vision

Access to and use of clinical data

Australia has highly developed IT systems for health data. While these systems are very challenging to link, a national Cancer Plan presents an ideal opportunity to build national infrastructure to overcome barriers to evidence-based care. There is an opportunity to change practice to use these data to drive changes in healthcare provision.

In order to develop an effective process for systematic, regular audit of cancer CQIs against agreed benchmarks for minimum standards of care, clinical data need to be continuously collected, semi autonomously (minimising burden on clinicians), providing as close to real time feedback for institutions as possible on their performance against key CQIs. Established systems such as Queensland oncology online (QOOL) is capable of this now but the process requires integration across jurisdictions with a national roll out and probably federal support to effect change.

The Lung Cancer Clinical Quality Data Platform (LUCAP) initiative seeks to collect clinical CQI data from the time of lung cancer MDT for benchmarking against agreed standards of care. LUCAP will also link with long term outcome data such as PBS and MBS. Institutions' CQIs will be directly compared (with adjusted data). The non-identifiable results will be published publicly, for patients and clinicians alike. LUCAP seeks to identify unwarranted variations in care and support institutions to improve where required. In doing so, LUCAP will change the clinical culture for lung cancer care from one of complicity with variable clinical standards and outcomes to one of quality, innovation and constant striving for improvement in outcomes.

The concept of LUCAP is directly translatable to any cancer type in Australia. LUCAP can act as a pilot, proof of concept project implemented at the 2-year phase of the Cancer Plan. Success against pre-defined KPIs can lead to the same concept and implementation with different cancer types with a vision for roll-out for multiple cancers, forming the basis of a self-regulating, learning healthcare system.

2 year vision: A national pilot CQI data platform is established for lung cancer as a proof of concept.

5-year vision: Other cancer types adopt CQI process

10 year vision: A cultural shift across all jurisdictions to patients and clinicians having access to their CQI data. This will require mandatory reporting, at a federal level. Use of this CQI data to systematically and regularly audit against agreed benchmarks for standards of care for all cancers in Australia.

Examples and learnings we can build on

National Lung Cancer Audit (NLCA), England and Wales

www.rcplondon.ac.uk/projects/national-lung-cancer-audit

Prospective collection and analysis of contemporaneous data have been used to drive improvements in the quality of care for lung cancer across the UK since 2005. Originally established in response to very poor national lung cancer outcome data, the National Lung Cancer Audit (NLCA) produces annual reports of CQIs across England and Wales. Annual reports have charted overall steady improvements in care, for instance, with more patients having access to surgery and chemotherapy. Measures of good practice have demonstrated incremental improvements over a ten year period (2005 vs. 2015), for instance histological confirmation rate (68% to 75%), proportion with subtyped NSCLC (64% to 87%), proportion receiving chemotherapy (45% to 60%), increasing surgical resection rates and correlating quality of lung cancer services with 1-year survival rates {all refs available through the website above}.

The NLCA has outstanding levels of National Health Service participation and collaboration with treating centres with 100% of incident cases of lung cancer accounted for in the Audit since 2016. In 2015 the Audit was adopted by the Royal College of Physicians (UK) as an exemplar audit of cancer care and the Audit has published more than 50 papers. The NLCA is widely acknowledged to be responsible for improvements in lung cancer outcomes in England and Wales, both at a local institutional level and to directly influence national policy (for instance increasing the numbers of thoracic surgery trainees to become consultants).

The Victorian Lung Cancer Registry (VLCR)

https://vlcr.org.au

The VLCR is a clinical quality registry that was established in 2011 and has expanded statewide to 19 health services and 49 hospitals capturing > 85% of all new Victorian cases of lung cancer and now contains >14,500 registrations. The VLCR reports[11] consistently highlight clinically important variations in care including imaging use prior to surgery, 30-day mortality after resection for NSCLC, advanced NSCLC patients in otherwise good health receiving SACT and patient centred outcomes such as screening for supportive care needs, discussion at multidisciplinary team (MDT) meetings, and even recently a lower adjusted mortality associated with MDT case discussion[12].

Cancer Alliance Queensland and Queensland oncology online (QOOL)

https://canceralliance qld.health.qld.gov.au/

The Cancer Alliance Queensland Safety and Quality program is a clinician led, safety and quality program for cancer across QLD, embedded in clinical care. Queensland oncology online (QOOL) was established in 2009 and is an integrated, unified and secure platform, combining systems and tools that include matching and linking to state registries, data standardisation, de-duplication and data enrichment of population wide clinical data. QOOL has automated integrated data from over 60 data sources. Currently in QLD alone 76 different MDTs across 14 public and private facilities are using QOOL to support multidisciplinary care. Anonymised CQI reports can be generated for public and private cancer services including outcomes based on best practice and guideline concordant care. QOOL is already available to every public institution in Victoria and Queensland and is expected to be established in

Western Australia (WA) by 2023. QOOL can provide the data collection component for a future national cancer CQI process.

LUCAP has established a strong working relationship with CAQ and is using QOOL for the WA pilot project. QOOL complements the aims of LUCAP, particularly in the quest for a cross-jurisdictional approach to data collection and analysis.

In conclusion

The LUCAP investigators strongly support and encourage a cultural shift in Australia to a data-driven, self-regulating, learning health system, with accredited cancer MDTs. Strong advocacy is required to change attitudes, culture and practice in the treatment of and funding for lung cancer in Australia.

On behalf of the LUCAP Investigator team,

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