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RESPONSE TO HEALTH LEGISLATION AMENDMENT

Response by Crohn's Colitis Cure to the Health Legislation Amendment (Modernising My Health Record - Sharing by Default) Bill 2024

Thank you for the opportunity to provide feedback on the Health Legislation Amendment (Modernising My Health Record – Sharing by Default) Bill 2024. This legislation represents a positive step forward in modernising Australia's healthcare system through improved data sharing, a principle central to our mission at Crohn's Colitis Cure's (CCCure) and exemplified by our flagship *Crohn's Colitis Care (CCCare)* digital clinical management platform.

About CCCure and IBD

Crohn's Colitis Cure (CCCure) is an Australian registered charity www.c-c-cure.org, with a mission to improve care now and be instrumental in cure for people living with inflammatory bowel disease (IBD).

IBD, including Crohn's disease (CD) and ulcerative colitis (UC), is a group of chronic inflammatory conditions predominantly affecting the gut. IBD affected approximately 1 in 290 Australians in 2016[1], however both its incidence and prevenance have been growing steadily over the last decade. It is now estimated that IBD will affect over 1% of Australians by 2030[2]. Of note, 10-20% of people with IBD are diagnosed before their 18th birthday with a peak incidence between 15-25 years. As IBD rarely decreases life expectancy, its epidemiology creates a very significant and extended Burden of Disease (BoD). IBD has no current cause or cure, and is characterised by diarrhoea, rectal bleeding, abdominal pain, fatigue, malnutrition, and resultant functional gastrointestinal, nutritional, and psychological comorbidities.

CCCure's experience with innovation of health data

Healthcare is undergoing a significant shift in how it operates, driven by the need to adopt emerging technology while remaining patient-centric and value-based. Data-driven healthcare, powered by accessible intelligence, will enable smarter, more personalised medicine. This will support a move away from the traditional *diagnose and treat* paradigm to *predict, prevent, and manage*. To enable this paradigm shift, particularly in chronic complex diseases like IBD, strategic investment in data infrastructure which are enmeshed in healthcare delivery ecosystems is crucial.

To achieve this, we at CCCure have reimagined how data are collected and used. Traditional collection methods are siloed, disconnected, and require double data entry, increasing the risk of errors,

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[1] Studd C, Cameron G, Beswick L, Knight R, Hair C, McNeil J, et al. Never underestimate inflammatory bowel disease: High prevalence rates and confirmation of high incidence rates in Australia. J Gastroenterol Hepatol. 2016 Jan;31(1):81-6. doi: 10.1111/jgh.13050.

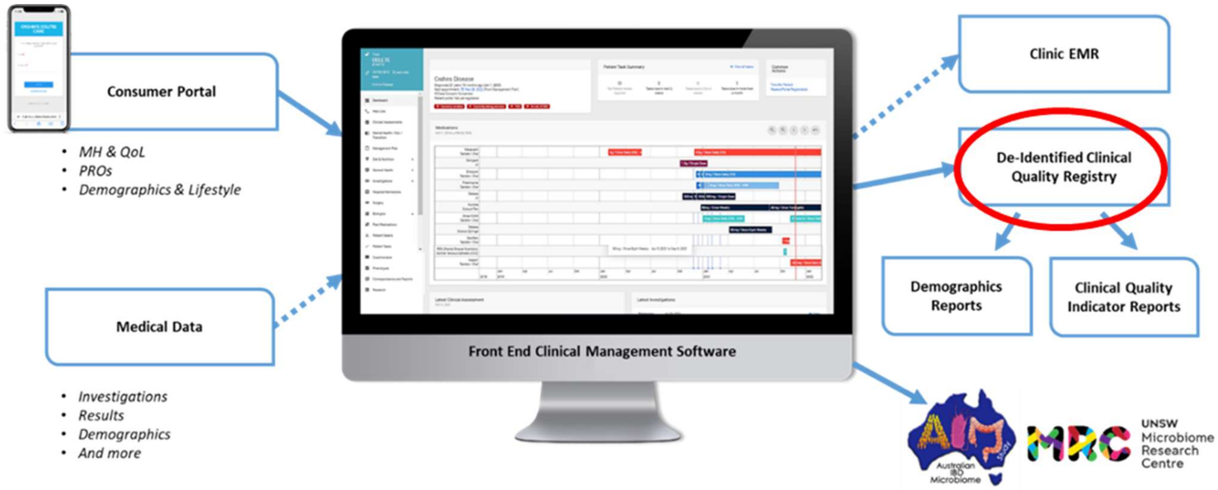
[2] Crohn's & Colitis Australia 2023. Inflammatory Bowel Disease Experts Call for Urgent Action to Ensure Equitable Multidisciplinary Care in Australia as Prevalence Continues to rise. CCA, accessed 15 May 2024, <https://crohnsandcolitis.org.au/2023/11/03/inflammatory-bowel-disease-experts-call-for-urgent-action-to-ensure-equitable-multidisciplinary-care-in-australia-as-prevalvence-continues-to-rise/>

omissions, duplication, and additional costs. Moreover, these methods lack the capability to implement innovations directly and rapidly into care pathways and analyse their effectiveness in real time. Thus, limiting the value of the data and perpetuating the long lag of translating research into care.

Unlocking the full potential of health data therefore requires not only intelligent data use but also, an approach which collects meaningful structured data as close to care as possible, ideally with active engagement from consumers co-contributing their own data. Adopting an integrated, interoperable, and adaptive omni-channel platform breaks down barriers and delivers smart data to create new value opportunities across the entire disease lifecycle. This self-evident need for comprehensive, real-time data led to CCCure creating the globally unique cutting-edge clinical management platform, CCCare. CCCare is a world-first, cloud-based, IBD-specific Electronic Medical Record (EMR) and linked Clinical Quality Registry (CQR) that collects consumer-level clinical data from clinicians and patients in real time, during routine care. Currently, CCCare is used over 20 sites across Australia (and is also available in New Zealand), with plans to expand to 70+ sites by 2028.

In support of CCCure's approach with CCCare, a recent paper from the European Crohn's and Colitis Organisation (ECCO) has underscored the need for standardized data collection to address current limitations in consumer, clinical, and research applications[3]. Siloed data with inconsistent tools and definitions hinder the development of meaningful insights for complex diseases such as IBD.

Non-Patient Identifiable Information (PII) data collected during routine care instantly flow through to the linked, longitudinal CQR. This is a significant point of difference from traditional CQRs which use secondary data entry and contain only a limited subset of data points. CCCare's unique approach allows detailed, real-time monitoring and evaluation of IBD care. This innovative model avoids traditional data silos, making it highly efficient for audit and research. CCCare also integrates patient-reported data to ensure inclusion of a consumer-centric view, facilitating both shared decision-making in care and consumer empowerment. This integration leads to safer, more consistent, affordable care, reducing repeat testing and errors resulting from lost or missed patient information.



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[3] Hanzel J, Bossuyt P, Pittet V, Samaan M, Tripathi M, Czuber-Dochan W, Burisch J, Leone S, Saldaña R, Baert F, Kopylov U, Jäghult S, Adamina M, Arebi N, Gecse K. Development of a Core Outcome Set for Real-world Data in Inflammatory Bowel Disease: A European Crohn's and Colitis Organisation [ECCO] Position Paper. J Crohns Colitis. 2023 Apr 3;17(3):311-317. doi: 10.1093/ecco-jcc/jjac136. PMID: 36190188

CCCure's alignment with Amendments

We understand the Bill's framework stems from the recommendations of the Strengthening Medicare Taskforce Report (2022), emphasising real-time access to health information as being foundational for a modern, connected healthcare system. This aligns with CCCure's purpose: leveraging integrated data to deliver equitable, high value healthcare.

Our CCCare platform already operationalises the principles underpinning this legislation and thus, CCCure is uniquely positioned to comment on and to contribute to the successful implementation of this reform. We seek to highlight some of the key provisions of the Bill and their importance as they relate to our platform.

Mandatory Registration and Data Sharing

The Bill requires healthcare providers to register with My Health Record and upload prescribed health information.

CCCare already operationalises the principles of "sharing by default" by integrating diagnostic, pathology, and clinical data into a unified system. This ensures that healthcare providers have real-time access to actionable insights, improving patient outcomes while reducing inefficiencies. Our platform demonstrates the benefits of mandatory data sharing which include streamlined care and reduced redundancies.

Integration with Medicare Benefits

Linking Medicare benefits to compliance with data-sharing requirements ensures alignment between funding and data-driven care. CCCare has demonstrated potential savings by reducing repeated diagnostic tests through integrated data sharing, directly supporting this aim.

This can be used to further drive system and cost efficiencies such as reducing the existing administrative burden in the approval and prescribing of advanced biologic therapies.

It should be noted that support is essential to create these linkages, as individual practices and not-for-profits cannot bear the cost alone without raising consumer healthcare expenses. Strategic investment by the Department now will reduce future costs and could be guided by a threshold or means-tested approach per provider.

Patient Rights and Exceptions

The Bill emphasises patient control over their My Health Record and includes exceptions for clinical discretion and patient preference. CCCure's enacts these principles through a patient-centred approach that ensures data sharing respects individual preferences, all while maintaining high standards of safety and care.

CCCare is built with patient autonomy at its core. We provide robust privacy controls, allowing individuals and clinicians to manage their data preferences while ensuring compliance with legislation and regulation.

Our platform actively supports care and is endorsed by clinicians – this enables consumers to understand its benefit in their care and has fostered a high-level of trust in both the CCCare platform and our organisation. Consumers report strong acceptance and support for the use of their data, with less than 1% of potential CCCare consumers opting out for privacy reasons.

Support for Providers and System Upgrades

The Bill allows extensions for providers to adapt to new requirements.

CCCure offers various methods to incentivise implementation. We note the disconnect between the clinical user/consumer and the administrator of the service provider as a major hurdle for consideration. Strategies to mitigate this challenge are discussed further in the recommendation section.

Compliance, Enforcement, and Financial Impact

We note that measures to ensure compliance and accountability are integral to the legislation.

CCCure has a range of measures to mitigate noncompliance with agreements. However, as noted above – the disconnect between the end user and the administrator responsible for compliance is the most significant barrier to overcome. Punitive measures alone are not the most effective solution for increased compliance. Strategies to mitigate this challenge are discussed further in the recommendation section.

Commentary on Alignment with Broader Legislative and Regulatory Changes

CCCure strongly supports the principles underlying the Health Legislation Amendment (Modernising My Health Record – Sharing by Default) Bill 2024. However, to fully realise the potential benefits of this amendment, it is essential to align its implementation with other critical legislative and regulatory frameworks including the *Australian Government Digital Health Blueprint 2023-2024***,** *the National Strategic Framework for Chronic Conditions* and the *National Strategy for Clinical Quality Registries and Virtual Registries 2020–2030*. A whole-of-system approach is crucial to improve health care access, affordability, and outcomes for all Australians.

Recent research indicates the number of digital health apps available globally stands at 337,000[4]. Although the rise of mobile and tele-health has been driven by the creation and use of consumer-facing digital apps for wellness and self-care, other segments now serve healthcare providers directly. These include the growing number of tools that aid clinical decision-making and software platforms for clinical care and research, such as CCCare.

The rise in digital health tools, coupled with the move by State and Territory health systems to adopt uniform EMRs and single patient identifiers creates an opportunity to improve the consistency, quality, and affordability of healthcare.

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[4] https://www.iqvia.com/insights/the-iqvia-institute/reports-and-publications/reports/digital-health-trends-2024?utm_campaign=2024_DigitalHealth_INSTITUTE_TC&utm_medium=email&utm_source=Eloqua

However, without careful implementation, these advancements risk exacerbating data and service delivery fragmentation, with data silos persisting at the service level because they fail to follow the consumer throughout their healthcare journey.

CCCure's experience in delivering a digital national whole of disease solution can provide valuable, practical insights for the implementation of a modernised My Health Record.

Data Interoperability

To maximize the utility of shared health records, the My Health Record amendment must prioritise data interoperability across all healthcare settings, including hospitals, primary care, private specialist rooms, allied health, and aged care. Significant barriers currently hinder seamless data exchange, leading to duplicate testing, missed diagnoses, and treatment delays.

A current example of this lost opportunity is that My Health Record cannot receive discrete data points with accepted medical definitions. When records such as chemical pathology arrive as an image or PDF format, established markers like rising creatinine (an early warning sign for renal failure) or falling haemoglobin (early sign of GI cancers) cannot be seen or used to prompt action. CCCare collects meaningful data which can be used for clinical insights but is unable to provide this crucial information to My Health Record in a useable format.

The Digital Health Blueprint underscores the urgent need for a national interoperable health system. The amendment should align with this vision by leveraging open data standards, robust Application Programming Interfaces (API), and international interoperability protocols to foster a more connected and efficient healthcare ecosystem. This can be as simple as agreeing to common data elements and definitions.

Key initiatives such as CSIRO's Sparked Data Interoperability Project demonstrate the transformative potential of harmonising health data across disparate systems and can serve as a blueprint for implementation. Integration with broader national strategies, including the National Strategy for Clinical Quality Registries and the National Framework for Chronic Conditions, is critical to ensure that the My Health Record system facilitates better care coordination, addresses inefficiencies, and supports data-driven decision-making.

By accelerating the development of national interoperability standards and secure messaging systems, and appropriately funding and supporting end users like CCCure, the amendment can position My Health Record as an essential piece of Australia's digital health infrastructure, enabling secure and seamless data exchange that improves health outcomes for all Australians.

Integration with Clinical Quality Registries (CQR)

High-quality health data is critical for tracking outcomes, evaluating interventions, and driving continuous improvement in care delivery. CQRs like CCCare play a pivotal role in these efforts, offering real-time, actionable insights into treatment outcomes, disease trends, and care inequities.

To maximize their impact, the My Health Record amendment should align with the National Strategy for Clinical Quality Registries, the National Framework for Chronic Conditions, and initiatives such as CSIRO's Sparked. To increase user interest and engagement, funding is required to ensure CQRs across all disease areas are expanded in coordination with My Health Record. This is especially important for chronic, underrepresented disease groups, and nascent registries in conditions with a high BoD, such as IBD.

By embedding these principles into the amendment, shared health data can more effectively integrate with CQRs, enhancing the ability to monitor national health priorities, address inequities in care, and inform targeted interventions for underserved populations. This alignment will drive system-wide improvements in care delivery, ensuring that registries remain powerful tools for improving healthcare quality and outcomes across Australia.

Chronic Disease Strategies

Chronic diseases, such as IBD, are among the leading contributors to healthcare costs and poor health outcomes in Australia.

There are no contemporaneous official national health economic data specifically addressing the BoD in IBD, although CCCure has recently provided data to Crohn's Colitis Australia (CCA) who will publish the first State of Nation report on IBD in February 2025.

In 2013, PwC estimated the national annual hospital costs for IBD to be in the order of $100 million, and annual productivity losses to be over $380 million[5]. An additional $2.7 billion of financial and economic costs have been associated with the management of IBD[5].

There is also ample high-quality data to demonstrates that the implementation of proactive care models in IBD can halve IBD hospital admissions, reduce length of stay, and decrease costs for those admitted[6,7,8].

Through CCCare and its CQR, care sites can easily track clinical quality indicators and benchmark against other sites to improve quality and safety. This is instrumental in reducing unwanted healthcare variation and ensuring that all Australians receive high-quality care, regardless of their location. To facilitate this process, CCCare offers live, real-time reporting to sites on IBD-specific KPIs (see image below).

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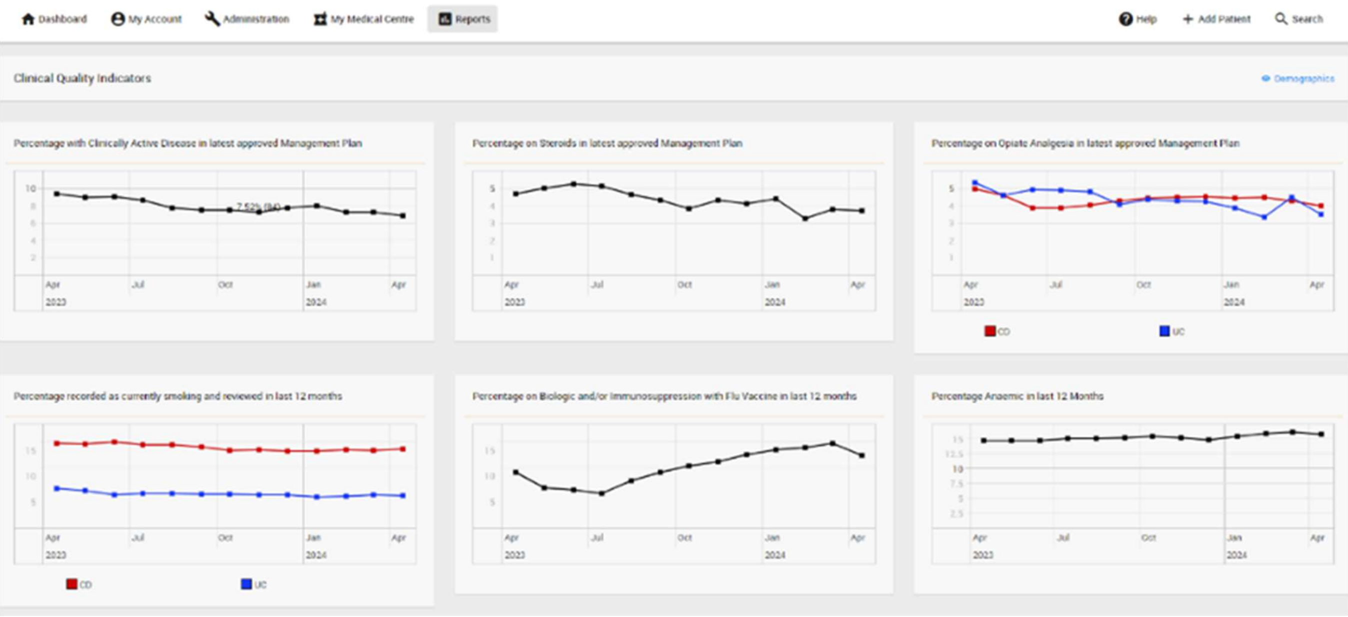
[5] Crohn's & Colitis Australia, 2013, *Improving Inflammatory Bowel Disease care across Australia.* [Online]. Available at: https://crohnsandcolitis.org.au/wp-content/uploads/2022/02/PwC-Report-2013-Executive-Summary.pdf

[6] Sack C, Phan VA, Grafton R, Holtmann G, van Langenberg DR, Brett K, Clark M, Andrews JM. A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease. J Crohns Colitis. 2012 Apr;6(3):302-10. doi: 10.1016/j.crohns.2011.08.019. Epub 2011 Oct 12. PMID: 22405166

[7] Phan VH, van Langenberg DR, Grafton R, Andrews JM. A dedicated inflammatory bowel disease service quantitatively and qualitatively improves outcomes in less than 18 months: a prospective cohort study in a large metropolitan centre. Frontline Gastroenterol. 2012 Jul;3(3):137-142. doi: 10.1136/flgastro-2011-100086. Epub 2012 May 1. PMID: 28839654; PMCID: PMC5517272.

[8] Karimi N, Sechi AJ, Harb M, Sawyer E, Williams AJ, Ng W, Connor SJ. The Effect of a Nurse-Led Advice-Line and Virtual Clinic on Inflammatory Bowel Disease Service Delivery: An Australian Study. Eur J Gastroenterol Hepatol. 2021; doi:10.1097/MEG.0000000000002249



Demonstrated gains at sites can be used to model likely gains at a national level. Collecting these data and applying them at scale can equate to ongoing savings and productivity gains.

To illustrate the significant cost-saving potential at a national level, it is worth noting that:

- a modest cost-saving of 5% equates to annual savings of a minimum of $5 million, and
- a reduction of lost productivity by a modest 2% would result in productivity gains of a minimum of $7 million a year.

The savings in IBD care alone would offset any costs in funding any national IBD CQR implementation or interoperability.

Therefore, to ensure that amendments to the My Health Record system truly benefit those who need it most, it is crucial to ensure funding and development of appropriate national clinical care standards alongside paired CQRs, as a parallel process. National standards provide a framework for consistent, high-quality care, and their paired CQRs allow data submission and audit to demonstrate adherence. These systems work in tandem to address the specific needs of patients with chronic disease, and incentivise increased use and value derived from My Health Record.

The proposed "sharing by default" framework must integrate with these Standards to enable real-time data sharing that supports proactive, coordinated, and patient-centred care. For diseases like IBD, these tenets can facilitate early diagnosis, multidisciplinary care models, and equitable access to emerging therapies and treatment pathways.

CSIRO's Sparked Project offers a model for harmonising health data across systems, ensuring the seamless exchange of information that underpins this initiative. To ensure expedited implementation, exemplars like the CCCare platform can be used.

The Digital Health Blueprint also highlights the transformative potential of digital infrastructure in managing chronic diseases.

Aligning the My Health Record amendment with the *National Framework for Chronic Conditions* and the *National Strategy for Clinical Quality Registries* will ensure that shared health data drives the implementation of necessary clinical care standards. This alignment will enhance care coordination, provide actionable insights into treatment outcomes, and promote the use of digital tools for patient self-management and monitoring.

By prioritising the development and adoption of national clinical care standards and benchmarking in conjunction the amendment, the government can create a more equitable and effective healthcare system. This will ensure that patients with chronic diseases like IBD receive timely, high-quality, and well-coordinated care, ultimately improving outcomes for those who need it most. Importantly, best care sites will be identifiable and able to assist others in improving their processes and obtaining better outcomes, thus driving down costs and reducing low value care.

Affordability and Techquity:

Achieving meaningful healthcare reform requires that the My Health Record amendment explicitly address affordability, equity, and *techquity* – the equitable distribution of digital health benefits across all populations. Techquity ensures that advances in healthcare reduce, rather than exacerbate, disparities in access, outcomes, and care delivery.

To realise this vision, the amendment must align with policies that expand telehealth services, enhance digital literacy, and invest in infrastructure tailored to rural, regional, and remote (RRR), and socioeconomically disadvantaged communities. These initiatives are essential to ensure that all demographics, particularly people and communities facing barriers, can benefit from the transformative potential of digital health technologies.

The Digital Health Blueprint underscores the critical role of digital health in increasing equitable access to care. The proposed "sharing by default" framework must integrate with these efforts to provide seamless access to telehealth services, real-time data sharing, and the technology required for full participation in the My Health Record system. Platforms like CCCare focus on equitability and exemplify the potential of leveraging real-time clinical data for equitable care delivery.

In further support, a 2024 publication on the implementation of a digitally-delivered, hospital-initiated, community-based prehabilitation program demonstrated opportunities to optimise care equitably. The digital program's evaluation demonstrated that commonly cited barriers to accessing digital initiatives such as relative socio-economic disadvantage and indigenous status were not found to be barriers to participation. Additionally, rural, regional and remote people, and older people were found to be just as likely to engage in well-designed digital tools as their counterparts.[9]

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[9] Journal of Orthopaedic Surgery. 2024;32(2). doi:10.1177/10225536241234032

Additionally, integrated data sharing can drive significant cost and efficiency gains by reducing unnecessary diagnostic tests, optimizing resource allocation, and minimizing waste. Furthermore, leveraging CQR's to conduct in-registry studies on models of care using real-world data will enable direct comparison of efficacy, safety, and cost across various treatment approaches. This approach is critical in discovering safer, lower-cost, and more effective care in a manner that cannot be achieved through traditional research studies alone.

Solutions like the CCCare platform showcase the significant ways in which digital health solutions can enhance the sustainability of Australia's healthcare system while addressing inequities. These efforts resonate with the *National Framework for Chronic Conditions* and the *National Strategy for Clinical Quality Registries*, emphasizing the importance of prioritising equity in healthcare reform.

The amendment must build on these successes by fostering a healthcare ecosystem that is not only inclusive but also efficient, ensuring that no community is left behind in the transition to a modernised, digital-first health system.

Recommendations for Implementation and adoption

The proposed My Health Record amendment should not be implemented in isolation. Its success depends on a collaborative, targeted strategy that places consumers and clinicians at the forefront, rather than focusing predominantly on large service providers and suppliers. High-need cohorts who have high healthcare resource utilisation such as IBD consumers should be prioritised for initial implementation. These groups have demonstrated pressing need, and an immediate potential to benefit from this change.

Organisations like CCCure prioritise the needs of consumers and clinicians over profit and have built trust beyond the public health system – they are critical partners for driving adoption and acceptance of these reforms.

Fund Interoperability in High-Need Groups

Achieving seamless integration requires targeted investment in interoperability, especially in high-need areas like IBD. Funding APIs to connect systems like CCCare—which provide meaningful and complementary health information—along with incorporating structured data fields, can significantly accelerate the adoption of My Health Record.

Support Providers Through Training and Resources

Empowering healthcare providers with intuitive tools and training that demonstrate the benefits of data sharing, rather than focusing on compliance, is essential for success. Campaigns developed in partnership with trusted organisations like CCCure can capitalise on existing high levels of consumer trust and clinician engagement. Additionally, leveraging CCCure's clinical teams, pathology networks, and consumer relationships across Australia will help build widespread understanding and acceptance.

Focus on Communication and Equity

Clear, transparent communication and targeted education campaigns are essential to building trust, especially among communities facing barriers. CCCure's expertise in engaging diverse stakeholders ensures that outreach strategies resonate across demographics, fostering inclusivity and reducing disparities in healthcare access and outcomes.

Facilitate Provider Adaptation

Non-profit organisations like CCCure face unique cost barriers in adapting to new digital frameworks. Providing targeted funding to support these transitions will enhance compliance, reduce implementation friction, and prove more cost-effective than broader measures.

Start with High-Need Areas

Conditions like IBD highlight significant unmet need and inequity, making them ideal starting points for the amendment's implementation. By addressing these areas first, the amendment can quickly demonstrate its value, build momentum, and refine processes for broader application. CCCare's success in creating interoperable systems for chronic disease management provides a practical, scalable model for national rollout. There are clear demonstrable cost savings and productivity gains that will offset any costs of implementation. In IBD alone, instance and prevalence continue to grow, and the number of Australians affected will soon rise above 1% of the population. In addition to improving the use of My Health Record, this amendment presents an opportunity to transform healthcare delivery.

Conclusion

CCCure fully supports the legislation's objectives and is eager to collaborate to ensure its successful implementation. Through the CCCare platform, we have already demonstrated the transformative potential of integrated health technology and data to improve outcomes, enhance equity, and drive efficiencies. We welcome further discussions to contribute to this vital reform.