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Health Forum
of Australia

Representing consumers on national health issues

eHealth: Let's Get it Right

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Consumers Health Forum of Australia

- **Advocates for appropriate and equitable healthcare**
- **Undertakes consumer-based research**
- **Raises the health literacy of consumers, health professionals and stakeholders**
- **Provides a strong national voice for health consumers and supports consumer participation in health policy and program decision making.**

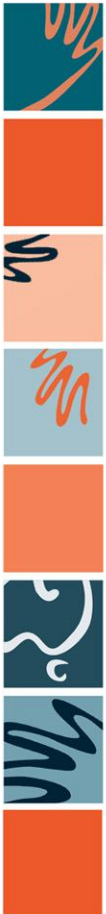




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Why eHealth?

- **Our health system is fragmented and under stress**
- **eHealth and PCEHRs can be the ‘digital glue’ for our health system**
- **Consumers are wary but interested in the benefits of eHealth and PCEHRs**
- **eHealth can achieve essential reform in information exchange across the health sector and between providers and consumers.**





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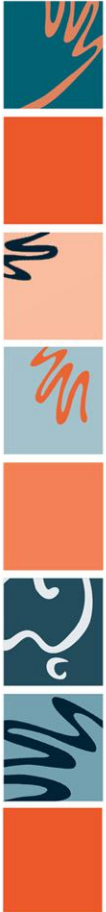
PCEHRs Will Have Real Benefits if Implemented Correctly

- Improving the safety and quality of healthcare
- Enabling consumers to access a variety of services seamlessly
- Building health professional and consumer confidence
- Putting the emphasis more on the consumer and less on the services being provided



What Consumers Need to Support PCEHRs

- **Key components of an effective implementation of PCEHR include:**
 - **Active engagement and involvement**
 - **Consumer entered information**
 - **Easily accessible information**





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What Consumers Need to Support PCEHRs



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A 'Personally Controlled' Record: Access Controls

- **Consumers want the 'No Access' control to be reinstated. It is central to consumer control**
- **Effective removal is not a solution**
- **For some, this is a "deal-breaker" in terms of participating**

Doctor, I would like to see my medical records in regard to the period when my systolic ejection murmur was heard at the 2nd right intercostal space.



I'm sorry sir, but I never show my patients their records because they lack the knowledge needed to properly interpret the information.




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A 'Personally Controlled' Record: Audit Trails

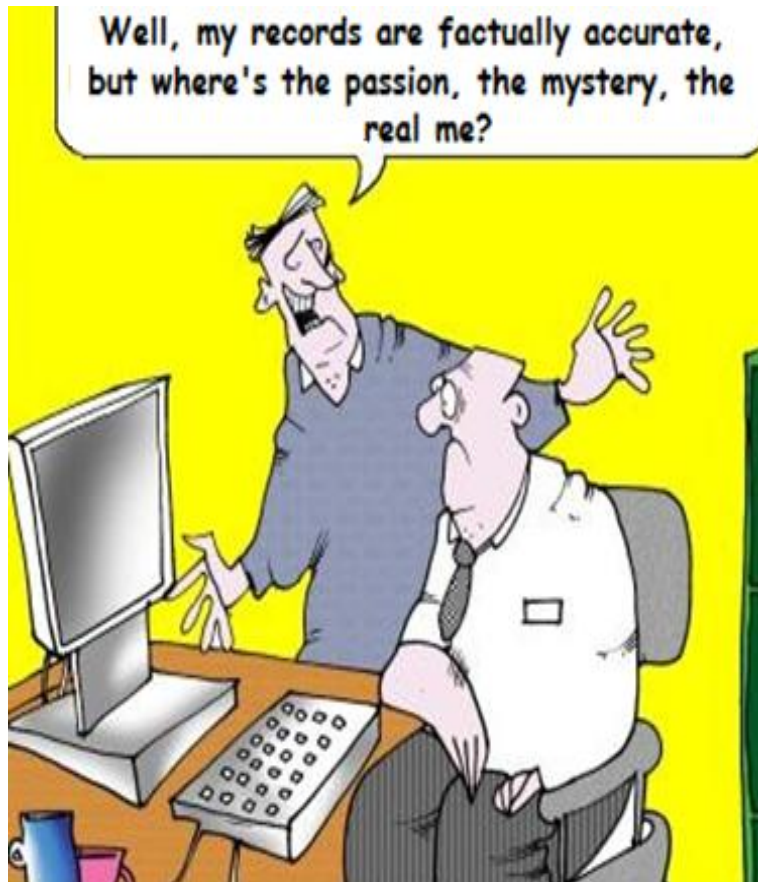
- **Audit trails could play a key role in building consumer confidence in the PCEHR**
- **However, the audit trail is of no use to consumers if they can't see who has accessed their information**
- **CHF has called for the audit trail to provide consumers with information on who has accessed their record. This will assist them in identifying breaches**





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A 'Personally Controlled' Record: Consumer Entered Data



- **Consumers want to be able to use the PCEHR to enter information and monitor their own health**
- **This could be a useful tool in encouraging consumers to register for a PCEHR**

A 'Personally Controlled' Record: A Consumer Driven Opt-Out System

- An opt-in model may not deliver the critical mass of users needed in order to make the PCEHR work for consumers
- An opt-out model with consumer activation puts the consumer in the driver's seat and encourages participation

If the success of the PCEHR system hinges on the adoption of an opt-out model, then CHF considers that it is the approach that Australia must take

A 'Personally Controlled' Record: Consumer Involvement and Ownership of the PCEHR System

- **There is no simple 'tick the box' solution to consumer engagement**
- **Consumer 'representation' must be complemented by real engagement and bottom-up consultation structures**
- **The PCEHR needs mechanisms that enable consumers and consumer groups to contribute to PCEHR system governance in the long-term**





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What Consumers Want from the PCEHR Legislation: Welcomed Inclusions

**The strengths of the Draft PCEHR
Legislation include:**

- **Details on interim governance arrangements, with the Secretary acting as the System Operator and Medicare Australia managing the PCEHR system**
- **Its foundation on the National Privacy Principles**
- **Penalties for misuse**



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What Consumers Want from the PCEHR Legislation: Key Concerns

- **Complaints handling**
- **Long-term governance**
- **Independence of the System Operator**





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Fundamental Lessons

- **Actively engage with health consumers if you want them to support eHealth and PCEHRs**
- **Assume health consumers are more interested in real health outcomes than the nature of service delivery**
- **Be prepared to demonstrate the benefit of new approaches to health consumers and not assume what is good for the system is good for individual consumers**





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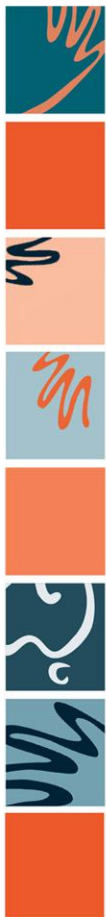
Conclusion

- **We must make the health system accountable for achieving real health outcomes**
- **This will require a significant system change in the way we approach health care**
- **Consumers must be moved to the centre of the health care system**
- **PCEHRs and eHealth are critical components in this much needed system reform**





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