

NHMRC Partnership Diagnostic Informatics

CONSUMER REFERENCE GROUP REPORT – 23 JUL 2018

The NHMRC Partnership Diagnostics Consumer Reference Group Workshop took place on the 23rd July 2018, at the Australian Institute of Health Innovation, Macquarie University. This inaugural consumer workshop adopted an innovative approach to enhancing the contribution of consumers towards understanding current challenges associated with test result management. The workshop was attended by ten consumer representatives and five researchers who formed three groups for workshop discussions.

TOPICS

The topics for the workshop were consumer driven and selected based on consumer choice of their relative importance. The two topics addressed during the workshop were:

1. Transitions of care - "I am aware of the next steps in my care" and
2. Access - "Do I have the information I need to understand the decisions being made?"



Participants were invited to engage in analysing interview excerpts from emergency department patients and clinicians, and staff in pathology and medical imaging departments discussing hospital test results management. This was an innovative approach adapted from traditional qualitative data analysis in which consumers annotated their initial thoughts on data excerpts before group discussions. Researchers guided consumers through the analytical process and facilitated discussion of potential themes using a range of scribing tools commonly used in qualitative analysis.

WORKSHOP AIMS

The purpose of the consumer reference group workshop was to:

- Engage consumers in qualitative health services research
- Provide a forum for consumers to generate key themes related to care transition and access in test result management
- Identify key consumer perspectives and experiences on the challenges they have faced with test result management

TRANSITIONS OF CARE - “I am aware of the next steps in my care.”

Workshop participants discussed this topic within individual breakout groups and shared their experiences and perspectives collectively with other participants. Key points raised in relation to the current health care system identified the fragmentation of care delivery where communication and coordination were lacking during transitions of care. In addition to the problems associated with the multiple providers involved in a patient’s care (e.g., medical, nursing and allied health practitioners across hospital-based and community settings, pathologists, radiologists etc.), consumers identified the following key factors:

- A lack of interoperability between information technology systems used within and between care settings.
- Limited provider knowledge about processes and roles between departments (e.g., ED and ancillary departments.)
- Lack of communication between providers in care coordination.
- Decreased focus on long term, “continuing” relationships with one GP because of the emergence of what one consumer referred to as “5-minute GP clinics” where patients are only allotted “5 minutes” per visit and see a different GP each time.
- Lack of standardisation of discharge summaries, which means the quality of documentation is variable. Alternatively, clinicians might not review all available information even when documentation is comprehensive.
- Lack of effective communication with patients and relatives/carers from providers including factors such as: ageist assumptions, patronisation of patients and carers, limited consideration of varying levels of health literacy and culturally and linguistically diverse (CALD) backgrounds, and the use of medical jargon. The time pressures in hospitals were also identified as a barrier to effective patient communication.



The interaction of the conditions and factors above contributed to the consumers’ perception that:

- There is an ambiguity of responsibility (of those involved in the test management process) as to who is responsible for the follow-up and actioning of test results, i.e., the assumption that “somebody will do it”.
- There is an increased onus on patients to ensure results are followed up, although responsibility to follow up was believed to ultimately lie with the doctor.
- Patient information can be lost in care transitions, leading to duplicate testing and further results to follow up.
- Providers make incorrect assumptions about information always arriving at its intended destination during care transitions, e.g., discharge summaries always reach the GP.

Moving forward, participants envisioned increased interoperability between health IT systems, and an electronic record which consolidated information from all providers, such as a “global care plan”, or a patient-managed health record with the capacity to accept proxy users (relatives or carers) if required. Ideally but subject to resources, hospitals would provide a dedicated staff member responsible for managing the entire patient journey (a generalist, nurse, or “health coordinator”) with a complete view of the patient care process. Other suggestions included providing tailored communication and opportunities for patient involvement based on individual consumer preferences and health literacy.

ACCESS - “Do I have the information I need to understand the decisions being made?”

Consumers agreed that adequate access to health information (including test results) was required to understand the decisions being made about their health. This carried implications for their participation in the care process and contribution to improved outcomes. Patients “can speak from a position of knowledge” regarding their health conditions, ask relevant questions to trigger further clinical thought or consideration of treatment alternatives, and act as an additional check against error alongside the clinician. Patient access to information could also prevent unnecessary repeat testing across health care settings, saving on costs and improving outcomes, e.g., avoiding unnecessary patient exposure to radiation, prevention of hospital acquired anaemia, more expedient clinical decision-making. However, participants described attributes of a perceived “culture” within the current healthcare system which created a number of barriers to information access. Notably, that:



- Access to one’s own information was not the default; patients must go to great lengths to request and access information, and this process is fraught with barriers e.g., cost, time, resources.
- The level of information made available to the patient was predominantly determined by providers, without consultation with patients; “staff make the assumption that the patient doesn’t need to know”.
- Patient information is managed as though it is the intellectual property of the healthcare service, but ownership should really lie with the patient; “it’s my body”.
- There is currently no culture of feedback about the experience of care; compounded by a

fear of potential repercussions (e.g., being labelled as “non-compliant”) if complaints are made or decisions of medical staff are questioned.

- Data on the health sector is predominantly used for measures of efficiency, not effectiveness or outcomes of care. Patients need to be made aware of the performance of hospitals and what outcomes they can reasonably expect from a procedure/site-specific episode of care.

Participants believed that healthcare providers should ensure they are familiar with current policies on access to health information (including the NSW Health policy on patient access to records and the Australian Commission on Safety and Quality in Health Care’s *Charter of Healthcare Rights*). Furthermore, participants made suggestions for improving the quality and nature of information dissemination to facilitate better patient understanding and meaningful engagement. Specifically:

- Presentation of information should account for health literacy, avoid jargon, and explain acronyms. There should be increased information on resources for support, further information, next steps in care, and information packs in lay terms detailing the hospital journey etc.
- Process of amending incorrectly recorded information should be simplified.
- Avoidance of a two-tier format of information release which may lead to patients being supplied with information that may be of inferior quality.
- Information must be released in a format that is useful and meaningful (i.e., not as a “data dump”), developed through increased consultation with patients to account for varying levels of health literacy. This is required to improve shared understanding and partnership with patients in the care process.

- More summary sheets created in medical records (especially for the chronically ill) to be used for future presentations: more likely to be read than entire records and lowers the cost of requesting records if summaries can be requested.
- Greater inclusion of relatives and carers, especially in certain demographics e.g., older people, people from culturally and linguistically diverse (CALD) backgrounds

ACKNOWLEDGMENTS

The research team would like to thank all attendees for their support and active collaboration. The feedback from participants was highly positive and favourable. The topics discussed provided a rich insight into consumer experience and expectations in test result management and will inform the future directions for research in this area. The outcomes of this workshop reinforce the value of consumer engagement in health research.

