

Factsheet: Julian's Key Health Passport Trial Evaluation

Background

Julian's Key Health Passport was developed by West Moreton Hospital and Health Service (WMHHS) in memory of a young man with intellectual and physical disability, Mr Julian Klass, who developed aspiration pneumonia at Ipswich Hospital and died in 2011.

Julian's Key Health Passport was developed to support people with disability to **communicate their healthcare needs** in a way that empowers them as individuals and provide **clarity for health professionals** and care teams and enable them to provide person-centred care.

Trial

In 2019, Queensland Health launched a trial of the Julian's Key Health Passport at Ipswich and Logan Hospitals to find out if the Passport:

- helps people with disability to communicate their healthcare needs and be more involved in their healthcare; and
- helps health professionals and others care for people with disability.

Evaluation

Deloitte Access Economics was commissioned to undertake an evaluation of the trial which was concluded in August 2021. The full evaluation report is available on request by emailing: DisabilityPolicy@health.qld.gov.au.

The evaluation report was based on data from a range of sources including stakeholder interviews, a survey of clinicians, non-government organisations and consumers, a documentation review and other usage data.

While the trial was not long enough to observe system change and for Julian's Key to become embedded in practice, the trial evaluation examined people's experience with the tool, identified strengths and weaknesses of the tool and its implementation, and made recommendations to inform the ongoing roll-out of Julian's Key Health Passport.



Key findings from the evaluation

Context

- The perception of care for people with disability within hospitals could be better, which would reduce hesitancy in seeking hospital care.
- The evaluation report notes that there have been a number of reports that have identified issues relevant to the care of people with disability in the hospital system. This includes the Queensland Public Advocate's review, *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland: A systemic advocacy report*, and the 2020 interim report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.
- Consistent formal processes for care for people with disability in clinical and hospital settings are needed. Where Nurse Navigators adopted this role, they are highly valued by consumers and their carers.
- Consumer experience of the tool varied depending on multiple factors, including the setting of care, level of clinician awareness, accessibility and time constraints.

Strengths

- There is general support for the Julian's Key Health Passport and wide acknowledgement of its potential. All stakeholders, and in particular consumers, see the value of Julian's Key to assist in the communication of care needs, to guide referral and handover, and deliver better informed person-centred care.
- The personalised aspects of the tool are empowering to the consumer and encourage ownership.
- Staff within the health system and support services who were exposed to Julian's Key reported increased awareness of care needs and improved ability to communicate with people with disability and their carers.
- Queensland Health branding and certifying of information within the tool empowered carers and consumers to assert their rights and care needs while in hospital.
- Downloads of the Julian's Key mobile application steadily trended upwards over time, with a preference for the paper version among both consumers and clinicians.

Room for improvement

- There is low awareness of Julian's Key among staff at trial Hospital and Health Services.
- Mobile application technology was favoured in the market at the time of development, however, other technology solutions have since been developed and should be explored.
- Julian's Key was not always used as intended, with completion of the tool often occurring post-acute episode in the hospital setting.
- The time cost to complete the tool was a barrier to uptake.
- There are other similar disability care summaries and communication tools available, and pre-existing documentation requirements. Tool fatigue may limit take-up by support workers working for non-government organisations.
- There were a number of challenges at the commencement of the trial, including governance issues, the impact of COVID-19 restrictions and early barriers to training implementation for clinicians which impacted clinician awareness of the tool.
- Greater involvement of people with disability in early formative design processes may have been beneficial in optimising the design and communicating the intended settings for use.

Recommendations from the evaluation

1. Ensure that the scope and purpose of Julian's Key as a communication aid is clear and differentiated from other health passports used across the system.
2. Promote disability awareness and appropriate responses to people with disability in the hospital setting through staff training and integration of initiatives and tools supporting people with disability.
3. Explore opportunities for active involvement of consumers in future design processes as consumer perspectives on the benefits of using the tool will be key to ongoing uptake and sustainability of Julian's Key and achieving its objectives.
4. Resolve ongoing technology solution management and development, considering continuity of access for consumers.
5. Explore opportunities to improve the tool for conciseness and accessibility for consumers and usefulness for clinicians.
6. Review barriers to uptake, including explicit acknowledgement of the benefits and risks associated with the inclusion of medication lists within Julian's Key. There is also a need to consider the ethical implications of health service workers assisting consumers to complete the tool, including risks related to information accuracy and clinical governance.

7. Provide clarity on the settings in which the tool may be used, e.g. in hospitals and the community.
8. Assist consumer advocates and support workers in promoting uptake among consumers within the community, in partnership with primary care and the disability sector.
9. Consider how Julian's Key utilisation may occur in conjunction with other disability comprehensive care plans and Comprehensive Health Assessment Program (CHAP) documentation.
10. Explore use of the Smart Referrals system and reimbursement mechanisms for primary care providers to raise awareness and uptake of the tool. This will reinforce that the community as the ideal setting for completion of Julian's Key, preferably developed over a period of time in consultation with General Practitioners and enabling input from multiple sources across allied health.
11. Incorporate Julian's Key into clinical processes and embed as part of a task-focused health service culture upon admission to hospital.

Overall Learnings

- Stakeholders consider the tool to be effective when used as designed in the appropriate management of healthcare of people with disability.
- There is a need for greater uptake and engagement with the tool among health and support services.
- The tool needs to be part of a holistic approach that embeds the appropriate culture, skills, and workforce to support the health care response received by people with an intellectual disability.
- The technology aspects and format of the tool need to be updated to make it more contemporary and user friendly.

Next Steps

- Queensland Health has accepted the findings and recommendations of the evaluation.
- Queensland Health is committed to implementing the evaluation recommendations and promoting the use of Julian's Key as part of an improved response to meeting the health needs of people with disability.