

Mental Health Carer Experience Survey (CES)

Presented by:
Sarah Kelshaw & Jonathan Harms



Topics

- ▶ The importance of measuring the experience of Carers
- ▶ Introduction to the Mental Health Carer Experience Survey (CES)
- ▶ How is the CES supported in NSW?
- ▶ Action and change
- ▶ Future developments



The importance of measuring the experience of Carers

- ▶ Carers experiences are especially important in mental health care due to the obstacles to consumers understanding (or acting on) their own needs as a result of their symptoms. Carer's mental and physical health is often impacted by their caring role, making them key targets for support.
- ▶ An overemphasis on the 'inner', subjective experiences of people with a lived experience of mental ill-health obscures the irreducibly relational nature of recovery. But taken to an extreme, the individualistic approach to mental health makes everyone responsible for their own illness (and their OWN recovery). *(Relational recovery: beyond individualism in the recovery approach Rhys Price-Robertson, Angela Obradovic and Brad Morgan, ADVANCES IN MENTAL HEALTH, 2016)*
- ▶ In fact interpersonal relationships suffuse all aspects of recovery, including experiences such as hope, identity and empowerment; and maintaining healthy relationships is therefore vital for achieving recovery. *(Relational recovery: beyond individualism, Price-Robertson et al)*



3

The importance of measuring the experience of Carers


- ▶ Further, in our current inadequately resourced mental health system, the gaps in service provision mean that family and carers often provide supports the public system fails to provide, or crucial supplements to what is available. This makes them crucial partners for health services to recognise and support, especially when their own mental health is vulnerable.
- ▶ When carers are involved, recognised and supported, they not only make a huge contribution to the recovery of the people they support, they also preserve their own well being.
- ▶ By understanding what supports the carers need for themselves and to better support their loved ones we can reduce the risks to all (consumers, carers and clinicians) and make our system, effective, efficient and humane.



4

Introduction to the CES

Service:



Mental Health Carer Experience Survey

This survey is about your experiences, as a carer **over the last three months**. By completing this survey, you will help the service better understand how to work with carers towards the recovery of mental health consumers. If you care for more than one person, just think of one of these people when completing the questionnaire.

WHO IS A CARER?

Carers can come from many different backgrounds but many never think of themselves as carers. Many feel they are doing what anyone else would in the same situation, looking after their family member, partner or friend. Carers are the family member, partner or friend of someone with a mental illness whose lives are also affected by that illness. Carers provide support and assistance to the person with a mental illness.

GETTING STARTED

Your responses to this questionnaire are anonymous. Your experiences are very important to us so we would like you to provide an answer to each question. But you can leave a question blank if you wish. There is space at the end of the survey for you to provide additional feedback about your experiences.

Please put a cross in just one box for each question, like this:

As a carer with a family member, partner or friend who had contact with this mental health service in the last three months, how often did the following occur?

	Never	Rarely	Sometimes	Frequently	Very frequently
1. You understood what you could expect from the mental health service for yourself and your family member, partner or friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. You were given an explanation of any legal issues that might affect your family member, partner or friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. You understood your rights and responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Your personal values, beliefs and circumstances were taken into consideration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. You were able to obtain cultural or language support (such as an interpreter) when you needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. You were given the opportunity to provide relevant information about your family member, partner or friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Your opinion as a carer was respected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



5

Introduction to the CES

- ▶ A national questionnaire that was developed in collaboration with carers
- ▶ Part of a suite of consumer and carer experience measures
- ▶ The CES asks carers about their experience of support and engagement by mental health services
- ▶ It focuses on the carer's experience NOT the carer's view of the consumer's experience
- ▶ The CES is designed to assist services and carers to work together to improve mental health services



6

Who is a carer?

- ▶ Carers are the family member, partner or friend of someone with a mental illness whose lives are also affected by that persons illness
- ▶ A person is not a carer if they are under a contract of service e.g. employee or volunteer
- ▶ Carers able to complete the CES are not limited to those recognised under the Mental Health Act ('designated carers' and 'principle care providers')



7



What areas of experience does the CES measure?

- ▶ CES questions are grouped into different categories or 'domains' based on what they measure

Making a difference

How the service contributed to outcomes for individuals including social and emotional wellbeing and physical health

Providing information and support

How the service works for the individual carer including resources such as written information, a care plan and access to peer support

Valuing individuality

How the service meets the individual's needs including sensitivity to culture, gender and faith and the importance of personal values and beliefs



8



What areas of experience does the CES measure?

Supporting active participation

How the service provides opportunities for engagement, choice and involvement in the process of service delivery

Showing respect

How the service provides the individual carer with a welcoming environment where they are recognised, valued and treated with dignity

NSW Additional Questions

In NSW, two additional multiple choice questions have been included:

Question 15 -

"You were given the specific information you needed for your role in the ongoing care, treatment and recovery of your family member, partner or friend"

Question 19 - (have you been given the following?)

"Information about the role and legal rights of designated carers and principal care providers under the NSW Mental Health Act 2007"



9

How is the CES supported in NSW?

- ▶ The CES is a joint project between the NSW Ministry of Health (InforMH) and Mental Health Carers NSW Inc.
- ▶ A CES Advisory Committee was established in 2017 to support the planning, implementation and ongoing support of the CES
- ▶ This committee has representatives from each Local Health District/Specialty Health Network, Carers and NSW Ministry of Health representatives. The committee is co-chaired by Mental Health Carers NSW and InforMH



10

Implementation in NSW

- ▶ Implementation of the CES started in NSW public mental health services in August 2018
- ▶ Since this time over 600 surveys have been completed
- ▶ The CES has been translated in 26 languages with further translation to be completed this year



11

Action and Change



12

Future developments

- ▶ CES pilot in CMOs
- ▶ eCES is currently in development



13

Questions?



14

Contact:

Sarah Kelshaw
Project Manager - InforMH
sarah.kelshaw@health.nsw.gov.au

Jonathan Harms
CEO – Mental Health Carers NSW Inc
Jonathan.Harms@mentalhealthcarersnsw.org

