

Person—informal carer existence indicator, yes/no/not applicable/unknown/not stated/inadequately described code N[N]

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Identifying and definitional attributes

Metadata item type:	Data Element
Short name:	Informal carer existence indicator
Synonymous names:	Informal carer availability; Informal carer existence flag; Carer arrangements (informal)
METEOR identifier:	787901
Registration status:	Aged Care , Standard 20/06/2023
Definition:	An indicator of whether a person has an informal carer , as represented by a code.
Data Element Concept:	Person—informal carer existence indicator
Value Domain:	Yes/no/not applicable/unknown/not stated/inadequately described code N[N]

Value domain attributes

Representational attributes

Representation class:	Code
Data type:	Boolean
Format:	N[N]
Maximum character length:	2

	Value	Meaning
Permissible values:	1	Yes
	2	No
Supplementary values:	97	Not applicable
	98	Unknown
	99	Not stated/inadequately described

Source and reference attributes

Submitting organisation:	Australian Institute of Health and Welfare
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Data element attributes

Collection and usage attributes

Guide for use:

Informal carers may include those people who receive a pension or benefit for their caring role and people providing care under family care agreements. Excluded from the definition of informal carers are volunteers organised by formal services and paid workers.

This metadata item is purely descriptive of a client's circumstances. It is not intended to reflect whether the informal carer is considered by the service provider to be capable of undertaking the caring role. The expressed views of the client and/or their carer should be used as the basis for determining whether the client is recorded as having an informal carer or not.

When asking a client whether they have an informal carer, it is important for agencies or establishments to recognise that a carer does not always live with the person for whom they care. That is, a person providing significant care and assistance to the client does not have to live with the client in order to be called an informal carer.

Collection methods:

Agencies or establishments and service providers may collect this item at the beginning of each service episode and/or assess this information at subsequent assessments.

Some agencies, establishments/providers may record this information historically so that they can track changes over time. Historical recording refers to the practice of maintaining a record of changes over time where each change is accompanied by the appropriate date.

Examples of questions that have been used for data collection include:

Home and Community Care (HACC) MDS

'Do you have someone who helps look after you?'

Disability Services NMDS

*'Does the service user have an informal carer, such as **family** member, friend or neighbour, who provides care and assistance on a regular and sustained basis?'*

Comments:

Recent years have witnessed a growing recognition of the critical role that informal support networks play in caring for frail older people and people with disabilities within the community. Not only are informal carers responsible for maintaining people with often high levels of functional dependence within the community, but the absence of an informal carer is a significant risk factor contributing to institutionalisation. Increasing interest in the needs of carers and the role they play has prompted greater interest in collecting more reliable and detailed information about carers and the relationship between informal care and the provision of and need for formal services.

This definition of informal carer is not the same as the Australian Bureau of Statistics (ABS) definition of carer or primary carer used in the Survey of Disability, Ageing and Carers (SDAC). The ABS definitions require that the carer has or will provide care for a certain amount of time and that they provide certain types of care. In SDAC, a carer is defined as a person of any age who provides any informal assistance, in terms of help or supervision, to an older person or someone who has a disability or a long-term health condition. This assistance has been, or is likely to be, ongoing for at least six months. A primary carer is someone aged 15 years and over who provides the most informal assistance to a person with disability with one or more of the core activities of mobility, self-care and communication. These definitions may not be appropriate for community services agencies wishing to obtain information about a person's carer regardless of the amount of time that care is for, or the types of care provided. Information such as the amount of time for which care is provided can of course be collected separately but, if it were not needed, it would place a burden on service providers.

Source and reference attributes

Submitting organisation: Department of Health and Aged Care

Relational attributes

Related metadata references:

Supersedes [Person—informal carer existence indicator, yes/no/not stated/inadequately described code N](#)

[Disability](#), Standard 29/02/2016

[Health](#), Standard 17/10/2018

Implementation in Data Set Specifications:

[Aged care person cluster](#)

[Aged Care](#), Standard 30/06/2023

DSS specific information:

Guide for use

Specific to the Aged care person cluster, the supplementary codes are described as follows:

CODE 97 NOT APPLICABLE

This code is used where the person's informal carer is a paid worker or a volunteer organised by formal services.

CODE 98 UNKNOWN

This code is used where the assessor or person collecting the information could not determine whether the person had a carer.

CODE 99 NOT STATED/INADEQUATELY DESCRIBED

This code is not for use in primary data collections.